Regulating the Genctic Supermarket: Preimplantation Genetic Testing, Parental Choice and the Harm Principle

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Abstract

In 1974, in one of the most intriguing footnotes in the history of political theory, Robert Nozick postulated the existence of a Genetic Supermarket, a state of affairs in which prospective parents would be able to choose – to whatever extent technology allowed – the genetic characteristics of their children. The closing decades of the Twentieth Century saw this thought experiment become a possibility, with developments in reproductive and genetic technologies allowing ex utero embryos to be tested for the presence of certain genetic traits before a decision as to which to implant. However, as technological obstacles to the unfettered choice envisaged by Nozick have disappeared, they have been replaced by regulatory barriers.

In this thesis, I examine the merits of a laissez faire approach to parental choice of offspring characteristics. Specifically, I consider the case for largely unrestricted access to preimplantation genetic diagnosis (PGD), the technology that currently offers most possibilities in this regard, and which has been the subject of most discussion and controversy. My examination is considered predominantly with the interests of the various parties who might be affected by such choices, and in particular, with the prospect of harm to any of them. In Chapter 2, I argue that if our concern is with the avoidance of harm, we should acknowledge that curtailing the range of choices open to prospective parents results in a harm to them. Hence, any such restrictions much be justified by reference to the risk of a greater harm which such restrictions will plausibly avoid.

In Chapter 3, I examine the purported harms that could be inflicted upon either those potential future children who would have been born but for their parents' use of PGD, or to the more tangible class of children who are in fact born as a result. With regard to the former, I argue that the attribution of interests (an essential prerequisite of harms) to merely potential beings is incoherent. Those children who are in fact born, however, are likely to be bearers of interests, and can therefore be the subjects of harm. Furthermore, I acknowledge that their unique origins, or the parental motives underlying them, could indeed see them faced with harms from which children born in more orthodox ways may be spared. However, it is my contention – a contention strongly influenced by the work of Derek Parfit – that such harms are likely to be outweighed by the benefits of existence, rendering it impossible to say of such children that they are harmed *on balance*.

In Chapter 4, I consider the possibility of harms being occasioned to other parties, specifically, existing disabled persons and those who are denied access to the Genetic Supermarket due to lack of financial means. With regard to the former, I suggest that while harms – both subjective and objective – cannot lightly be discounted, a laissez faire approach which sees the state adopt a position of neutrality with regard to the selection of traits may diminish rather than exacerbate these. Likewise, considerations of justice create unease about the prospect of a Genetic Supermarket accessible only by the wealthy. This, however, forces us to confront wider questions about undeserved advantage, and leads me to ask whether the Genetic Supermarket approach would be any more unjust than the status quo.

In my final chapter, I look critically at the decisions arrived at thus far by the various bodies charged with regulating access to PGD. In particular, the provisions of the Human Fertilisation & Embryology Act 1990, and the decisions of the Human Fertilisation & Embryology Authority which it established, are scrutinised. It is my contention that the decisions of the latter are sometimes inconsistent and difficult to reconcile with the ethical principles that they purport to uphold. In particular, they lack a coherent notion of harm, or of the duties that we owe to future persons.

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Table of Contents

Chapter 1 Introduction

References to revolutions are fast attaining the status of cliché in the field of bioethics. Certainly, the literature is already replete with references to revolutions, of the sexual,[1] reproductive,[2] genetic,[3] and information varieties. Whether the use of this term is always appropriate, or whether its impact is in fact being diluted by over use, is something of a moot point. What is beyond dispute is that developments in the fields of science and technology have radically altered the lives of a significant number of people, and seem destined to affect many more.

These changes have taken a variety of forms, but if they are linked by any common thread, it is perhaps that they have all resulted in ever greater degrees of control being placed in human hands. Whatever one's view as to the extent to which these 'revolutions' should be welcomed, what cannot be denied is that they have introduced a degree of choice into areas of life which previously lay entirely outwith human control.

The word 'choice' is not used here in a value-laden sense; its introduction into these areas is not, at this point, being depicted as something to be welcomed or regretted. As will be seen, there are those who would contend that there are certain matters which should, for a variety of reasons, not be subject to human control. Nor is any assumption being made as to the question of *which* particular humans exercise this choice. It may be that, in certain areas, the net result of the 'revolutions' has been to narrow rather than expand the range of choices available to the majority, while increasing the amount of power collected in the hands of an elite. Nonetheless, what cannot be denied is that much of what was previously determined by chance, or God, or natural selection, depending upon one's perspective, is now decided upon by human beings.

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[1] See Smith, Patricia. 'The Metamorphosis of Motherhood', in Joan C Callahan, ed. *Reproduction, Ethics, and the Law: Feminist Perspectives*, Indiana University Press, 1995, at p.110 for one example.

[2] Singer, Peter, and Wells, Diane, *The Reproductive Revolution*, Oxford University Press, 1994, and Chadwick, Ruth, 'Having Children: Introduction' from her collection *Ethics, Reproduction and Genetic Control*, Routledge, 1990, are just two out of literally hundreds of examples of works which have used of this term.

[3] E.g., Callahan, Daniel, 'The genetic revolution,' *Hastings Law Journal* (1994) v.45, 1435-1526.

This thesis is concerned with an area where reproductive and genetic technologies interact to present a set of choices which have never before been available to humankind: choices about what kind of people will comprise the generations which succeed us. Advances in understanding of the role of genetics in shaping human characteristics, together with developments of genetic screening techniques, have given rise to a situation wherein predictions can be made, often with substantial degrees of accuracy, about the characteristics of persons who are not yet in existence. Genetic testing[4] of embryos, or even of the gametes which will combine to create embryos, can reveal information about the life expectancy, health, sex, appearance, and even behavioural traits of the persons which those embryos could become.

Occurring in tandem with this, developments in reproductive technologies, particularly in vitro fertilisation (IVF) techniques, have given rise to situations wherein human embryos can be created in a laboratory environment, and stored there until such time as the prospective mother wishes them to be implanted. Since, as will be explained presently, IVF invariably involves the creation of several embryos, choices will arise as to which of these 'rival' embryos will be implanted in the uterus of a prospective mother. When combined with the genetic screening technologies alluded to above, the possibility exists for Preimplanation Genetic Diagnosis (referred to hereafter as PGD), whereby the prospective mother and/or some other party or parties, may make the decision whether to implant any of the embryos, and if so which ones, in the light of a considerable amount of knowledge about their genetic composition.

It is the choices created and the questions posed by the techniques of PGD with which this thesis is concerned. That such choices provide the potential for ethical controversy hardly needs to be said. However, an intriguing question which frequently arises in discussions about controversial technological innovations is whether the problems which they present are in fact entirely novel, or whether it is

[4] Throughout this thesis, I use the term 'genetic testing' in preference to 'genetic diagnosis'. Although the rejected term is more common in the literature, it may be seen to carry connotations ill suited to the context in which I will use it; in particular, 'diagnosis' may be thought to imply that the trait in question is in some sense pathological, which will in many cases be to beg the question, and in others (such as sex selection) be manifestly inappropriate. Nonetheless, the acronym PGD will be retained, in view of its familiarity and ubiquity in the literature.

the case that they merely reframe old questions in a new context. Is it perhaps the case, it is asked, that while the details change, the fundamental issues remain the same?

Many of the questions with which this thesis deals are far from being wholly new. On the contrary, questions regarding what makes a life valuable, whether life can ever be said to be worse than non-existence, and what (if any) duties are owed to future generations have intrigued writers for many years, and have received many more detailed considerations than they will receive here. More specifically, philosophers and science fiction authors, together with groups with decidedly more sinister agendas, have in the past considered the implications of being able to determine the nature of future persons.

What has changed in more recent times is quite simply that the questions have emerged from the realm of the purely hypothetical. The aforementioned 'revolutions' in scientific understanding, in technological applications of that understanding, and in social attitudes have seen the answers to these questions assume a degree of practical significance unknown at any previous time. Questions which were previously no more than admittedly fascinating thought experiments have become practical dilemmas in need of very real answers. 'For the first time in human history,' one observer has noted, 'the future existence of humanity as such has become a matter of choice'[5] while expressing the view that '[b]y providing us with the knowledge and ability to control the timing of pregnancies, modern science has endowed our generation with an unprecedented power of deciding ... the identity of people in a far from trivial sense.'[6]

The objective of this thesis is to consider some of these questions in the light of one particular ethical concern, a concern that will be explained in Chapter 2, and will be expounded upon in considerably more detail as this work progresses. For the moment, the major questions which will be addressed should perhaps be stated.

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[5] David Heyd, *Genethics*, University of Los Angeles Press, 1992, at p.8.
[6] Ibid, at p.10.

Robert Nozick, in what is surely one of the most intriguing footnotes in modern philosophical writing, referred in *Anarchy, State and Utopia* to the notion of a 'genetic supermarket.'[7] In keeping with the central arguments of that text, his suggestion here was that choices about what sort of people there should be [8] should be left in the hands of private individuals, and should not be determined or restricted by the state. This free market in genetic screening would meet 'the individual specifications (within certain moral limits) of prospective parents,'[9] and would possess 'the great virtue that involves no centralized decision fixing the future human type(s).'[10]

The technological means actually to shape or alter the genetic attributes of specific future children, such as gene therapy, remain largely within the realms of the hypothetical.[11] But the advent of PGD of in vitro embryos has, practically speaking, brought Nozick's dream somewhat closer. The technique was 'developed in the 1980s ... primarily in response to requests for help from people at risk of passing on a serious genetic disorder to their children.'[12] It involves the removal of one or more cells (blastomeres) from embryos generated in vitro, at about the 8-cell stage (usually around the third day after fertilisation).[13] The DNA from the biopsied cells is then amplified, originally by the technique of Polymerase Chain Reaction (PCR),[14] but in more recent times by Fluorescent In Situ Hybridization (FISH),[15] and examined before any decision will be made as to which of the various 'candidate' embryos to

[7] Robert Nozick, *Anarchy, State, and Utopia* (Basil Blackwell, 1986 edition), at p.315n.
[8] To slightly paraphrase Jonathan Glover's title.
[9] Nozick, *Anarchy, State, and Utopia*, *op cit.*
[10] Id.
[11] Although somatic gene therapy has been performed with some measure of success in a few cases; see Nils Holtug, 'Altering Humans - The Case For and Against Human Gene Therapy' *Cambridge Quarterly of Healthcare Ethics* (1997) 6, pp.157-174.
[12] Human Genetics Commission, *Choosing the future: genetics and reproductive decision making*, July 2004, at paragraph 3.14.
[13] 'Preimplantation Genetic Analysis', Robert A. Kaufmann, et al, *The Journal of Reproductive Medicine* (1992) 37(5);428-436, at p.428.
[14] For a straightforward account of how PCR works, see Philip Kitcher's *The Lives to Come*, Allen Lane The Penguin Press, 1996, at p.160.
[15] Karen Sermon, André Van Steirteghem, Inge Liebaers. 'Preimplantation genetic diagnosis', *The Lancet* (2004); 363(9421): 1633-1641, at p1633; Dagan Wells, 'Advances in preimplantation genetic diagnosis', *European Journal of Obstetrics & Gynaecology and Reproductive Biology* (2004); Vol. 115, Supplement 1: S97-S101

implant.[16] As the Human Genetics Commission explains, in the United Kingdom, 'PGD is currently being offered for three major categories of disease including:

- to determine the sex of the embryo with the aim of avoiding sex-linked disorders such as Duchenne muscular dystrophy;
- to identify embryos with single gene disorders such as cystic fibrosis;
- and to identify embryos with chromosomal disorders, where a technique called fluorescence in situ hybridisation (FISH) can be used to identify or confirm abnormal chromosomal rearrangements.'[17]

At present, twelve centres in the UK are licensed to carry out PGD. Between 2001 and 2004, the technique is believed to have brought about 45 live births in the UK,[18] while it has been claimed that over a thousand PGD births have occurred worldwide.[19]

The most straightforward, and common, type of test has involved ascertaining the sex of the embryo.[20] Certain genetic disorders are X-linked, meaning that they are only inherited by male offspring; a technique which ensured that only female embryos were implanted would similarly ensure that the unwanted condition was not passed on to the next generation.[21] The pre-implantation diagnosis of single-gene defects and chromosomal disorders has, however, also been successfully accomplished.[22]

Quite evidently, PGD is only an option to those who have undergone IVF, or some other means of assisted conception which results in a number of embryos being located ex utero. The present difficulties in achieving successful pregnancies following IVF have led some commentators to the conclusion that demand for PGD will, at least in the short term, be limited to those who already know they are at risk of passing on some genetic disorder, together with those who would be making use

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[16] Id.
[17] Human Genetics Commission, *Choosing the future: genetics and reproductive decision making*, July 2004, at paragraph 3.16.
[18] Ibid, at paragraph 3.14.
[19] John A. Robertson, 'PGD: New ethical challenges' *Nature Reviews Genetics* (2003); 4(1): 6
[20] Hanson, C., Hamberger, L., & Janson, P.O. 'Is Any Form of Gender Selection Ethical?' *Journal of Assisted Reproduction and Genetics* (2002); 19: 431–432.
[21] Of course, the ability to implant only embryos of the desired sex could be utilised for 'non-therapeutic' purposes. This highly controversial possibility will be considered in due course.
[22] Asangla Ao, 'Preimplantation genetic diagnosis of inherited disease', *Indian Journal of Experimental Biology* (1996) 34:1177-1182, and Hanson and Hamberger, op cit.

of reproductive technologies in any event.[23] Nonetheless, the distinct possibility exists that, as the success rate of techniques such as IVF improves, and the range of genetic conditions for which screening is possible continues to expand, so too will the demand for this technology.

In essence, the contention which I seek to explore could be summarised thus: that there is no need, or indeed justification, for restrictions to be placed upon unfettered access to such a Genetic Supermarket *in order to prevent any actual or likely harm that such access would cause*. Phrasing the contention in this manner demonstrates immediately some of the self-imposed limitations of this inquiry. It is not my intention to consider the notion of the Genetic Supermarket from every conceivable ethical perspective, nor to attempt to address every possible ethical concern to which such an entity might be thought to give rise. Rather, the far more modest scope of this thesis is to consider the question of harm; whether the Genetic Supermarket is likely to prove harmful, who precisely are the likely victims of that harm, whether and how that harm can be offset against likely benefits deriving from the Supermarket, and – at least as important as any of these other questions – how the law presently does, and prospectively should, respond to the possibility of harm deriving from it.

That the possibility of harm is a weighty concern in any evaluation of such an enterprise might be regarded as sufficiently self-evident as to obviate the need for further justification. Nonetheless, one of the first tasks undertaken in Chapter 2 will be to show that the language of harm is a common feature not only of bioethical discussions of PGD, but also of approaches adopted by the legislature and regulatory bodies to such questions. It will, I suspect, become apparent that the notion of harm has not always been invoked with any great conceptual clarity within such evaluations, nor has it been applied with any great consistency.[24] It is, nonetheless, almost a ubiquitous element within any such discussions.

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[23] Jiaen Liu, et al, 'Cystic fibrosis, Duchenne muscular dystrophy and preimplantation genetic diagnosis'. *Human Reproduction Update* 1996, 2(6);531-539.

[24] See in particular the comparison between Section 13(5) of the Human Fertilisation & Embryology Act 1990, and the attitude of the Court of Appeal to the 'wrongful life' action in *Mackay*, considered in Chapter 3, and also the contrasting reactions of the Human Fertilisation & Embryology Authority to the respective attempts of the two families who sought to use PGD to select a donor sibling.

In much the same way, it might be considered that 'harm' is a sufficiently clear concept as to need little by way of further definition or clarification. It is a concept familiar to legal scholars from the realms of tort/delict, while in lay parlance the term is commonly employed as a synonym for 'hurt' or 'damage'.[25] While in common use the term serves us well enough without further definitional efforts, though, the application of the concept of harm to the area of PGD requires a more precise understanding. Is it, we must consider, possible to harm a being that does not yet exist? Or one which lacks even basic awareness? Can someone be harmed by being born into adverse circumstances, if the alternative was never to be born at all? Perhaps most puzzling of all, is it meaningful to speak of a choice as 'harmful' even when we cannot point to an individual who is rendered worse off as a consequence?

Answering these questions is necessary if we are to address the central contention of this thesis, and this invariably requires grappling at close quarters with the meaning of harm, a task that will be undertaken in Chapter 2. Yet while this is necessary to evaluate that contention, it is not, I submit, sufficient. For the contention asks not only whether any harm is likely to result from a Genetic Supermarket approach to PGD, but whether such harm is sufficient to justify, or even require, regulation. A view that any harm, however trivial, should be prevented by law is not only likely to strike most readers as an overreaction, but furthermore, is rendered untenable by the realisation that the imposition of legal restraints may itself constitute a harm. As Chapter 2 will explain, in such circumstances, the harm inherent in legal restraint gives rise to a presumption against such restraint, i.e. a rule that restraint is justified only where it will avoid harm of a certain (predicted) magnitude.

Having considered what is meant by harm in Chapter 2, in Chapter 3 I will consider the question as to which parties could be meaningfully considered as the potential subjects of harmful actions. A number of candidates will be considered, some of which will be looked at in more detail in subsequent chapters. One of the primary objectives of this chapter, however, will be to consider whether several groups of purported interests which are regularly referred to are in fact valid objects of ethical

concern; indeed, in some cases, the question must be addressed as to whether such 'interests' are not entirely illusory. An example of such a category of purported interests, I will argue, are those sometimes attributed to those potential children who might have been born but for the existence of the Genetic Supermarket.

A different, and more tangible problem arises in relation to those children who are in fact born as a result of their parents' choices. Such children have been suggested to be at risk from numerous possible harms, but broadly speaking, these can be divided into two classes: those deriving from the very fact of being the product of such a decision, and those deriving from specific decisions determining the genetic traits they possess. As to the former, it may be thought that a child of the Genetic Supermarket – what the media often erroneously though memorably refer to as 'designer babies' – will be burdened with unfair parental expectations, or that he or she will feel less in control of his or her life than other children. With regard to the latter category of expectations, this relates to those (presumaby rare) situations where parents make 'harmful choices', a possibility rendered more plausible by the efforts employed by a Canadian couple to ensure the birth of a genetically deaf child.

These various child-centred concerns differ both in terms of how likely they are to materialise and in how grave the consequences would be should they do so. However, I will argue in Chapter 3 that both can be answered in terms of a harm-centred, person-affecting approach that places emphasis on the range of alternatives available to *these* children. My arguments here will be influenced by the well-known (though often rejected) thought experiments of Derek Parfit. His Non-Identity Problem gave rise to counter-intuitive conclusions about, inter alia, family planning, young teenaged mothers and our responsibilities to future generations. Its application to the realm of genetic choices renders inevitable conclusions that are likely to be no less difficult for some readers to accept.

Chapter 3 will also address some of the challenges to the Non-Identity Problem (which I attempt to fashion into a less negatively perceived Non-Identity *Principle*), before concluding with a brief consideration of some even more counter-intuitive

[25] I will argue in Chapter 2 that both of these lay uses are problematic as definitions, the former being too

outcomes which, I suggest, must result were this principle to applied with absolute consistency to its logical conclusions.

Central to the case in favour of the Genetic Supermarket is the assumption that, whatever other consequences follow from it, the freedom to avail themselves of it constitutes an important interest of the prospective parents. Is this, though, an assumption that we can readily make? For decades, the technolologies that allowed prenatal screening, and the counselling that preceded them, have been subject to criticism from feminist commentators and others less than convinced that the purported extension of choice which such technologies bring is in fact an accurate reflection of the reality. For writers like Barbara Katz Rothman, concern must be paid to the possibility that the manner in which such 'options' are presented – indeed, the very fact that they *are* offered – can create an environment of 'coerced voluntariness', which sees the choices available to potential parents – and potential mothers in particular – reduced rather than expanded. If there is validity in this claim, then rather than the interests of the potential parents tilting the balance in favour of a Genetic Supermarket, those interests would constitute a reason (though not necessarily a persuasive one) to regulate or curtail it.

In my concluding chapter, I will evaluate some of the claims that the availability of PGD restricts rather than expands the range of choices available to potential parents, and in particular, to potential mothers. In doing so, however, it is important to bear in mind that the focus of this thesis is not only on whether harm results from unregulated genetic choice, but ultimately on whether stricter legal regulation is likely to improve matters. Even if it is shown that the development of PGD technology has made the position of potential parents worse rather than better, it does not automatically follow that closing of access to it now that it is known to exist is the right course for the law to adopt. The latter part of Chapter 6, then, will be given over to a consideration of what, if anything, could be done to maximise parental autonomy.

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restrictive, the latter to wide.

My (predictably contentious) claim in Chapter 3 is that, in almost all circumstances, the child of the Genetic Supermarket does not sustain harm, or at least does not sustain a balance of harm over benefit, even where the choices his or her parents made were of the nature that many would consider damaging (such as genetic deafness). This conclusion derives from the realisation that, for this particular child, the alternative to life with these particular obstacles was no life at all; the implicit assumption here is that, with a few rare exceptions, life in these circumstances is better, for the child living it, than no life at all. Perhaps the most widespread concerns about free access to PGD are, however, somewhat less specific than those considered in Chapter 3. It is, for example, argued by many the actual choices which parents will in practice make will harm certain sections of society. This concern arises from the strong suspicion harboured by many that, given a choice of characteristics, the vast majority would select from a fairly narrow grouping, resulting in those who do not conform to these standards coming to be viewed as in some way 'defective.' Most commonly, this concern arises with regard to that large and disparate grouping labelled by our society as 'the disabled.'

Laura M. Purdy, for example, writes of the notion that there is a possibility 'that if we attempt to avoid the birth of children with disease or disability, we will harm those who already exist.'[26] This harm may take a variety of forms. 'At the most practical level,' Purdy writes, 'some believe that acting so as to avoid such births will lead us to reduce the social resources now allocated to the disabled. At a more theoretical level, the judgement that life is better without such problems is taken as an insult to those now facing them.'[27]

I propose in this chapter that the suggested harms to existing disabled people may be divided, loosely, into two varieties, which I refer to as 'objective' and 'subjective' harms. While the former would, were they to materialise, derive from certain measurable trends that would flow from the Genetic Supermarket, the latter depend upon certain attitudes and perceptions shared fairly widely within what some writers refer to as the 'disability rights community'. Since they are so conceptually distinct, it

[26] Ibid, at p.312.
[27] Id.

may come as no surprise to discover that I adopt a different response towards, and conclusion about, these respective categories. Thus, while any writer seeking to defend the Genetic Supermarket hypothesis must demonstrate that the 'objective' harms *will* not come about, the 'subjective' harms have, to an extent, already occurred, insofar as certain disabled people already feel offended, hurt or devalued by the existence of PGD, or some of the uses to which it is put.

While not disputing that such sentiments do indeed amount to harms, my approach will be, first, to consider whether they are, in fact, always fairly attributed to the availability of PGD, and secondly, to ask how best the law might act so as to minimise such harms. In particular, I consider the possibility that the best means of addressing these 'expressivistic concerns' would be by adopting a less rather than more restrictive approach to PGD.

The broad category of third parties thought to be at risk of harm from the laissez faire approach of the Genetic Supermarket is not, however, confined to those opposed to PGD. Rather, there also exists a credible case for the belief that certain parties have interests that could be negatively affected by the choice of potential parents *not* to use this technology. The contention that parents are subject to an ethical obligation to refain from 'burdening' the public purse with ill or disabled children is not as commonly encountered in academic bioethical literature as the 'expressivist' type concerns, but it nonetheless is an argument that we might expect to hear advanced with increasing frequently as the possibilities offered by this technology became more widely known. In this section, I will consider whether it is coherent to speak in terms of such a duty, what form it may take, and whether it may be thought to outweigh the potential parents' own interests in having the child of their choice.

Finally, this chapter will address what is perhaps the most abstract of all the potential harms considered in this thesis: the harm inherent in, or derived from, the unjust consequences of the laissez faire approach. The brevity of this section should make it immediately clear that it is by no means a thorough consideration of the various conceptions of justice that may be thought to be touched upon by the Genetic Supermarket. Such an evaluation would, I concede, require at least one dedicated

thesis to itself. Instead, I confine my discussion to a fairly brief consideration of the sorts of objections that are commonly levied, together with a few observations based upon my understanding of one influential approach to questions of justice and the distribution of natural talents and burdens, that proposed by John Rawls. Does a Rawlsian concept of distributive justice, I enquire, lead inevitably to the conclusion that the Genetic Supermarket is unfair? And if so, how best do we respond to that unfairness? Are there, perhaps, alternatives to legal restriction that are less burdensome or more effective at redistributing unchosen traits, or at least the undeserved benefits and burdens that accompany them?

In Chapter 5, my final substantive chapter, I turn to the question of how, in practice, the regulation of PGD has evolved in the UK, and in particular, the extent to which it has followed or departed from the laissez faire path. In an attempt to illustrate the ethical thinking that has underpinned the approach of the Human Fertilisation and Embryology Authority (HFEA), the body charged with dispensing the licences necessary for the carrying out of PGD, and hence, effectively, the doormen of the Genetic Supermarket. I consider in depth, by way of illustration, two particular applications for licences to carry out PGD, respectively, those from the Hashmi and the Whitaker families. Despite their ostensibly analogous nature, the two applications met with diametrically opposing responses (at least until the HFEA's very recent volte face in respect of Whitaker-like cases). Scrutiny of these cases, I will suggest, offers valuable insight into the concerns and considerations that lie behind the HFEA's decisions, and ultimately, casts a degree of doubt upon the coherence and consistency of those decisions.

Chapter 2 A Harm-Based Approach

The question at the heart of this thesis, then, asks whether a 'free market' in PGD is likely to result in any harm. As I sought to make clear in the Introduction, it is by no means my contention that the question of harm is the only question worth asking in relation to this technology. Yet there are, I would suggest, valid reasons for undertaking a scrutiny of PGD through this particular ethical lens.

As I will endeavour to demonstrate in this chapter, ethical theories that either have harm at their core, or that pay some significant attention to the notion of harm, form part of a lengthy and honoured tradition in Anglo-American legal theory, stretching back to John Stuart Mill (and beyond). More recent theoretical works may have rejected the monistic approach of Mill and his successors, which saw harm as perhaps the *only* justification for state intervention with private choices, but even those pluralist writers frequently count the avoidance of harm as an important ethical consideration, albeit one among several.

At least as important as the prevalence of the notion of harm in bioethical and jurisprudential literature is the prominent place it occupies in those very decisions that have permitted, prohibited or restricted access to the Genetic Supermarket. Both the statutory provisions governing reproductive technologies, and the body set up to oversee its enforcement, have made repeated and significant use of the notion, although as I will argue, in the case of the latter, not always with great conceptual clarity or consistency. For both of these reasons, then, I submit that consideration of the potential harmful consequences of PGD is a valid undertaking.

In the remaining part of this chapter, I intend to explore the notion of harm in greater depth, distinguishing different senses in which the concept is used, and in particular examining the interest-based notion of harm brought to prominence by Joel Feinberg.

2.1 Why harm?

While it may be that few judges, politicians or members of regulatory bodies are overt adherents to the Harm Principle (explained later in this chapter), it is clear that the concept of harm occupies an important role in the decisions which have in practice regulated decisions about the creation of new lives. Perhaps most obviously, this can be seen in the legislation which governs reproductive technologies and use of embryos, the Human Fertilisation and Embryology Act 1990, Section 13(5) of which stipulates that

> A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for a father), and of any other child who may be affected by the birth.[1]

While 'welfare' is not synonymous with 'harm', it is perhaps difficult to conceive of any calculation of welfare that does not take account of harm, even as it sets out to balance these against potential benefits. This contention is lent support by the interpretation of 'welfare' adopted by the Human Fertilisation & Embryology Authority, and its Ethics Committee (the latter of which is considered in more detail in Chapter 5). In its most recent Code of Practice, the HFEA made clear and specific reference to the risk of harm to the child as a possible reason for denying access to reproductive technologies:

> Those seeking treatment are entitled to a fair assessment. Treatment centres are expected to conduct the assessment with skill and care, and have regard to the wishes and sensitivities of all those involved. This assessment is expected to take into account the following factors relating to patients:
>
> ... (v) the risk of harm to children including
>
> (a) inherited disorders or transmissible disease
> (b) multiple births
> (c) problems arising during pregnancy
> (d) neglect or abuse
> (e) the effect of a new baby or babies upon any existing child of the family.[2]

[1] This subsection is at present the subject of a public consultation by the HFEA; see http://www.hfea.gov.uk/AboutHFEA/HFEAPolicy/ReviewoftheWelfareoftheChildPrinciple.
[2] Human Fertilisation & Embryology Authority, Code of Practice, 6th Edition, 2003, available at http://www.hfea.gov.uk/HFEAPublications/CodeofPractice/Code%20of%20Practice%20Sixth%20Edition%20-%20final.pdf, accessed 13.7.04.

As I will argue in Chapter 5, the HFEA's use of the concept of harm is far from unproblematic, but it is clear that it is a concept that features prominently in its reasoning. The most recent evidence – for the Authority's concern with harm, and perhaps also for its confusion over the concept – can be found in its decision to license PGD for those who wish to use it only for 'tissue typing'. The specifics of those decisions will be considered in Chapter 5, but for the time being it is sufficient to note that the Authority's Press Release couched its change of policy in the language of one particular conception of harm - 'harm as damage' - its initial unwillingness to permit this use being attributed to 'a concern about a potential risk of damaging the embryo.'[3]

It is interesting to note that, at the time of the Authority's initial decision about tissue typing, no significance was attached, either by the Authority itself or its Ethics Committee whose advice (on this matter) it ignored, of any such danger arising from the procedure itself. However, the Ethics Committee's approach was, once again, clearly informed by considerations of welfare, of which an evaluation of potential harm clearly played an important part:

> the Ethics Committee had in fact identified the 'putative child's actual moral, psychological, social and physical welfare' as an issue of great significance.[4]
>
> Its Report considered both a fairly traditional formulation of the 'welfare principle', asking 'whether the outcome of the technique adversely shifts the balance of benefit and harm'.[5]

There is evidence, also, that consideration of harm informs Parliamentary debates surrounding reproductive and genetic technologies, and PGD in particular. A very recent series of interviews conducted by the House of Commons Science & Technology Committee provides some evidence that concerns about harm remain a prominent consideration of the Committee's deliberations, as the following questions asked by members of the Committee suggest:

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[3] 'HFEA agrees to extend policy on tissue typing', 21 June 2004, at http://www.hfea.gov.uk/PressOffice/Archive/1090127358, viewed 26 July 2004.
[4] Ethics Committee of the Human Fertilisation and Embryology Authority, *Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors*, 22 November 2001, at paragraph 3.2.
[5] Ibid, at paragraph 2.14.

> If a proper social research study found that gender selection caused no harm, would you support it?[6]
>
> Would you support it [sex selection] if it was found there was no harm caused?[7]
>
> May I ask what evidence there is in the scientific literature that there is harm to donor conceived children from not being able to trace their genetic parent?[8]
>
> In your evidence you do mention that you feel gender selection inflicts no harm on the child, family or society. If there were any research which indicated that this was not the case, would it change your views?[9]

While the views and concerns of the Select Committee are not necessarily reflective of those of the wider legislature, it would perhaps be surprising if they were entirely divorced from them.

Although not directly related to the legislative or regulatory processes, the views of major professional and other prestigious bodies on such matters display a concern with potential harmful consequences. In its submission to the Select Committee on the subject of tissue typing, the British Medical Association noted as a 'key concern … the possibility of psychological harm resulting to the child who would be selected and born to be a donor', though it also acknowledged that 'these hypothetical risks of harm needed to be balanced against other harms, primarily the real harm to the

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6 Question asked by Robert Key during Oral Evidence Taken before the Science and Technology Committee, on Wednesday 23 June 2004, at http://www.publications.parliament.uk/cgi-bin/ukparl_hl?DB=ukparl&STEMMER=en&WORDS=fertilis+harm+&COLOUR=Red&STYLE=s&URL=/pa/cm200304/cmselect/cmsctech/uc599-ii/uc59902.htm#muscat_highlighter_first_match, viewed Sunday, 18 July 2004.

7 Id.

8 Question asked by Evan Harris during Oral Evidence Taken before the Science and Technology Committee, on Wednesday 23 June 2004, at http://www.publications.parliament.uk/cgi-bin/ukparl_hl?DB=ukparl&STEMMER=en&WORDS=fertilis+harm+&COLOUR=Red&STYLE=s&URL=/pa/cm200304/cmselect/cmsctech/uc599-ii/uc59902.htm#muscat_highlighter_first_match, viewed Sunday, 18 July 2004.

9 Question asked by Geraldine Smith, recorded in Minutes of Evidence Taken Before Science and Technology Committee, Wednesday 30 June 2004, at http://www.publications.parliament.uk/cgi-bin/ukparl_hl?DB=ukparl&STEMMER=en&WORDS=fertilis+harm+&COLOUR=Red&STYLE=s&URL=/pa/cm200304/cmselect/cmsctech/uc599-iii/uc59902.htm#muscat_highlighter_first_match. Viewed: Sunday, 18 July 2004.

sibling who would suffer or die without this treatment.'[10] In addition, the Royal Society of Edinburgh considered the potentially pivotal effect of evidence of harm to the embryo if PGD were employed:

> It is not clear, however, on what basis there should be restrictions of PGD to only serious clinical conditions, although there may be practical reasons for wishing to do so. If there are clinical reasons for undertaking PGD at all—and given that the consultation document itself notes in paragraph 26 that few people are likely to choose it—there appears to be little logic in limiting its use to certain conditions. Of course, this balance might change if it became clear that PGD caused significant harm in large numbers of cases. The balance would then perhaps shift towards not permitting it in "minor" clinical conditions because of the greater harm caused by using it—namely the additional damage to, or destruction of, the embryo.[11]

2.1.1 Harm in bioethical literature

In the realm of bioethical literature, concern with the avoidance of harm has a long tradition. As Beauchamp and Childress explain, the 'obligation not to inflict harm on others' is '[o]ften proclaimed the fundamental principle in the Hippocratic tradition of medical ethics', yet its precise origins are somewhat uncertain; the Hippocratic Oath certainly does not accord a prominent role to this principle.[12] Nonetheless, the maxim *primum non nocere* appears to be widely accepted as a core tenet of medical ethics.

Within the contemporary literature of bioethics, concern about the avoidance of harm is widespread, occupying some role in a variety of ethical traditions. Most obviously, adherents to the Harm Principle regard harm as *the* necessary prerequisite of any legal intervention with individual liberty. As discussed below, this view is perhaps less popular than once it was, having been supplanted to some extent by pluralist,

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[10] Memorandum from the British Medical Association to the House of Commons Science & Technology Committee, May 2004, available at http://www.publications.parliament.uk/cgi-bin/ukparl_hl?DB=ukparl&STEMMER=en&WORDS=fertilis+harm+&COLOUR=Red&STYLE=s&URL=/pa/cm200304/cmselect/cmsctech/599/599we13.htm#muscat_highlighter_first_match, at Paragraph 33, viewed Sunday, 18 July 2004.

[11] Memorandum from the Royal Society of Edinburgh to the House of Commons Science & Technology Committee, May 2004, at http://www.publications.parliament.uk/cgi-bin/ukparl_hl?DB=ukparl&STEMMER=en&WORDS=fertilis+harm+&COLOUR=Red&STYLE=s&URL=/pa/cm200304/cmselect/cmsctech/599/599we04.htm#muscat_highlighter_first_match

[12] Tom L. Beauchamp and James F. Childress, *Principles of Medical Ethics*, Fifth Edition, New York, Oxford University Press, 2001, at p113.

utilitarian and rights-based approaches, but nonetheless, a small but respected body of bioethical literature persists which advocates just such a view. Max Charlesworth, Emeritus Professor of Philosophy at Deakin University, has based his consideration of bioethical issues around a decidedly Millian approach:

> In a liberal society people should as far as possible be allowed to make their own moral decisions for themselves and it is not the business of the law to enforce a common code of morality. The law should be brought in, so to speak, only when other people are likely to be harmed in some obvious way.[13]

Heta Häyry has expressed her approach in somewhat different terms, and in particular does not couch it in the language of harm, but there are clear similarities between her 'liberal utilitarianism' and the harm-based approach adopted by Charlesworth:

> individuals should be left free to make their own choices, provided that the consequences of their decisions are not likely to have a negative effect on the basic need-satisfaction of others.[14]

Whether Häyry would agree to applying the term 'harm' to having 'a negative effect on the basic need-satisfaction of others' is a moot point, but it is clear that her approach shares the liberal presumption of adherents to the Harm Principle, and shares also their view that that presumption can be rebutted *only* to avoid adverse consequences for others.

For Charlesworth and Häyry, then, the presence of harm (or adverse consequences) to others is the only legitimate basis for state interference with individual liberty. More commonly, harm features as an element of a less narrowly focused approach to ethics. For ethical pluralists like Tom Beauchamp and James Childress, the obligation to avoid the infliction of harm – expressed as the principle of 'nonmaleficence' – is one of the four core ethical principles,[15] not derived from, nor either superior or inferior to, the others. Furthermore, the notion of 'harm' with which Beauchamp and Childress are concerned is remarkably similar to that adopted by 'harm theorists' like Joel Feinberg; thus, they 'construe harm exclusively in the

[13] Max Charlesworth, *Bioethics in a Liberal Society*, Cambridge, Cambridge University Press, 1993, at p74. See also p86, in relation to surrogacy.
[14] Heta Häyry, *Individual Liberty and Medical Control*. Aldershot, Ashgate, 1998, at p.99.
[15] Together with respect for autonomy, beneficence and justice.

second and nonnormative sense of thwarting, defeating, or setting back some party's interests.'[16]

As distinct from some of the utilitarian commentators, who question the distinction between acts and omissions, Beauchamp and Childress reject the idea that nonmaleficence (avoiding harm) and beneficence (the conferring of benefit) should be incorporated into one principle.[17] However, they also reject the assumption implicit in the *primum non nocere* principle that the former obligation should automatically take precedence over the latter:

> In general, if in a particular case the injury inflicted is very minor ... but the benefit provided by rescue is major ... then we tend to think that the obligation of beneficence takes priority over the obligation of nonmaleficence.[18]

In this, they are closer to those utilitarian commentators who are also concerned with balancing benefit and harm. John Harris has explicitly rejected the idea of the Harm Principle:

> The decision to "criminalize" conduct is surely principally a question of the utility of so doing. The issue is most sensibly decided by weighing up the social, political, and moral consequences of using the apparatus of the criminal law and of imposing the stigma and social consequences of criminality on offenders. We should not predetermine this issue by deciding in advance that if conduct is not harmful it is not criminal.[19]

It is not overly far-fetched to suggest that Harris's concern with 'the social, political, and moral consequences' of criminalisation could, at least to a large extent, be rephrased in terms of the language of harms and benefits, a contention that may to some extent be borne out by the fact that the remaining eleven pages of the chapter in which Harris makes this claim are given over almost entirely to defining the concept of 'harm.'

2.1.2 Harm and 'moral conservatism'

[16] Beauchamp and Childress, *Principles of Medical Ethics*, op. cit., at p116

[17] 'In our view, conflating nonmaleficence and beneficence into a single principle obscured relevant distinctions.' Ibid, at p114.

[18] Id.

[19] John Harris. *Wonderwoman and Superman: The Ethics of Human Biotechnology*, Oxford, Oxford University Press, 1992, at p86.

Perhaps the most interesting development in the evolution of harm-based ethics in recent years has been the apparently tacit acceptance of its central premise by those who might be seen as the successors of the 'conservative' opponents of Mill and Hart. Bernard Harcourt expounds the plausible thesis that the Harm Principle is no longer the exclusive property of 'liberals', but has been appropriated by supporters of further regulation – he refers to 'conservatives', though this category includes such unlikely candidates for that epithet as radical feminists. Rather than casting their arguments in classic, legal moralist terms, that would view the behaviour in question as 'being inherently immoral'[20] modern conservatives frequently couch their cases in terms of the purported harm the disapproved-of behaviour is thought likely to cause. Harcourt provides contemporary examples of the language of harm being invoked in opposition to decriminalisation of prostitution and homosexual freedom – both causes which liberal champions of the Harm Principle such as Hart would have supported.

In relation to bioethical issues at the beginning of life, a similar phenomenon can be observed. In a recent submission to the House of Commons Select Committee on Science and Technology, the Society for the Protection of Unborn Children (Great Britain) phrased their concerns in these terms:

> .The Abortion Act 1967 is based on the assumption that abortion will cause less mental or physical harm than continuing a pregnancy in some cases. This assumption is without evidentiary support. In fact scientific and anecdotal evidence suggests that the contrary is true, that many women are being hurt by abortion, thereby making abortion an inappropriate medical response to crisis pregnancy.[21]

The statement goes on to make specific reference to evidence purporting to show '"marked, severe or persistent" psychological or psychiatric disturbances' and '[d]eliberate self-harm', 'depression and substance abuse',[22] breast cancer,[23] cervical

[20] Joel Feinberg, *Harmless Wrongdoing*, Oxford, oxford University Press, 1988, at p8.
[21] Memorandum from the Society for the Protection of Unborn Children (Great Britain) to the House of Commons Select Committee on Science & Technology (June 2004), at http://www.publications.parliament.uk/cgi-bin/ukparl_hl?DB=ukparl&STEMMER=en&WORDS=fertilis+harm+&COLOUR=Red&STYLE=s&URL=/pa/cm200304/cmselect/cmsctech/599/599we38.htm#muscat_highlighter_first_match, viewed Sunday, 18 July 2004, at Paragraph 1.2..
[22] Ibid, at Paragraph 1.3.
[23] Ibid, at Paragraph 1.4.

resistance, placenta praevia, preterm births, ectopic pregnancy and potential infertility problems,[24] marital and other relationship problems leading to relationship breakdowns, general conflict and sexual dysfunction.[25] The ideas that abortion might be intrinsically morally wrong, or that it contravenes any particular religious dictate, are not advanced at all in the submission.

As Harcourt demonstrates, this new willingness of conservatives to take up the challenge of the Harm Principle has driven liberals to take up new weapons, most commonly the language of rights, in attempts to respond to the 'evidence' of harm pointed out by their opponents. He points to a leading US Constitutional law case dealing with pornography, in which the judge accepted evidence that pornography is likely to be harmful, but held that it was this very quality of dangerousness that demonstrated its status as the sort of speech that must be protected.[26] Rather than dispute the empirical premises of the conservative position (in this case, presented by feminist lawyer Catherine MacKinnon) the judge shifted the debate onto a different terrain, allowing him to contend that the mere presence of harm was not sufficient to justify a prohibition in the face of a constitutionally-protected freedom.

Whether the presence of likely or actual harm is sufficient to justify restrictions of choice in relation to PGD is an issue of obvious importance for legislators in this area, and I am in no way contending that harm is the *only* important consideration in this area. However, in an important sense, beginning with an exploration of harm may nonetheless be a valid approach. For it may be seen that, insofar as liberal judges and commentators have abandoned the rhetoric of harm for that of rights, this has been the result of a strong conservative empiricist response to the original liberal challenge to demonstrate some concrete harm. In those areas where such a challenge has never really been taken up by conservatives – in relation, perhaps, to sterilisation of consenting adults or atheism – the conservative case, at least in the 'democratic world', has become peripheral and ineffective (there have been no serious legislative

[24] Ibid, at Paragraph 1.5.
[25] Ibid, at Paragraph 1.6.
[26] *American Booksellers Association Inc. v Hudnut* 771 F.2d 323 (7th Cir. 1985), per Judge Easterbrook.

attempts to outlaw either contraception or atheism in Europe in recent years, despite the fact that both are strongly opposed by powerful religious bodies).

This trend demonstrates two phenomena of interest for the purposes of this thesis. First, it adds weight to my core contention that the question of harm remains one of wide and considerable relevance. If religious conservatives, radical feminists and classical liberals alike now seek to couch their arguments – at least partially – in terms of harm, then a consideration of the possible harm resulting from a practice like PGD will predictably interest many observers, even if it will, on its own, rarely be determinative of the issue for any of them. Secondly, it may suggest that at least some of the debates framed in other terms – about rights, for example – arise only after consensus that some issue of harm is at play. Harcourt's example of the pornography debate in the USA suggests that the 'free speech liberals' were pushed into arguing in terms of rights only after the conservatives/feminists had met their initial challenge and identified some possible harm.

This latter contention, I concede, is considerably more tentative than the former, and it may be that a discussion about harm is not invariably a necessary precursor to one about rights. It would seem, though, that at least some of the time ethical controversies have moved onto discussions about rights only after some measure of agreement that harm is at least a real possibility.

The first section of this chapter, then, has sought to demonstrate that a consideration of the possible harms involved in PGD is a worthwhile endeavour, in part because concern about harm continues to occupy a prominent place in bioethical literature (albeit increasingly only one of several prominent places). Perhaps more significantly, however, a consideration of possible harm involved in this technology is valuable because that is one of the foremost considerations in terms of informing the judgements already being made about how PGD should be regulated, by legislators, by the HFEA, and by those august bodies (such as the BMA and the Royal Society of Edinburgh) whose opinions might be expected to have a bearing on the legislative and regulatory decisions. It is my contention that such decisions have not invariably been informed by clear thinking about precisely what 'harm' might

mean, or how it might arise from decisions such as those under discussion - a contention I will seek to substantiate in later chapters.

2.2 'Harm' defined

Since the question central to this thesis concerns the possibility of harm resulting from the Genetic Supermarket approach to PGD, it is important to clarify precisely what is meant by 'harm'. At first glance, this may appear sufficiently self-evident as to obviate the need for further discussion. It should, however, soon become apparent that the term is far from uncontroversial.

2.2.1 Harm in its derivative sense

In common parlance, the verb 'to harm' is often used as a synonym for 'to damage'; it is, for example, both commonplace and intelligible to enquire 'will this weedkiller harm my lawn?' Whether a notion of harm can be extended to beings or objects which possess no awareness of being harmed is an important decision, as will be seen when attention is turned in the next chapter to whether we can say embryos are harmed when they are destroyed. For, in much the same way as herbicide may 'harm' a lawn by killing it outright or retarding its growth, so too might the destruction of embryos, or the prevention of their development such as by cryopreserving them, be thought to 'harm' an embryo.

Joel Feinberg, whose work has been so influential in exploring the notion of harm, is quick to distinguish, and dismiss from his consideration, this notion of harm in its 'derivative or extended sense', that is, 'the sense in which we can say that any kind of thing at all can be "harmed."'[27] This is the sense in which harms can be attributed to asentient, and possibly even, inanimate objects, such as when we say 'frost does harm to crops'.[28] As Feinberg explains, 'this is harm in a transferred sense; we don't feel aggrieved on behalf of the windows or the tomatoes, nor are they objects of our sympathies. Rather our reference to their "harm" is elliptical for the harm done to those who have interests in the ... crops.'[29]

[27] Joel Feinberg, *Harm to Others*, Oxford University Press, 1994, at p.32.
[28] Id.

For in the absence of an interest in growing or developing, how are we to conceive of a change in the status of the lawn or the crops as being welcome or unwelcome? Certainly, being sprayed with herbicide may well retard the growth of a field of grass, but relative to what ethical principle are we to judge this retardation problematic? For Feinberg, it is a straightforward matter to exclude these suggested instances of 'harm', since the purported victims do not possess a quality that he regards as a prerequisite of being 'harmed': the capacity to be a bearer of interests.[30]

2.2.2 Harm as set-back to interests

On Feinberg's conception, what distinguishes 'harm' from other ways in which we can affect an object – such as 'damage' or 'break' – lies in the requirement that the victim of 'harm' must possess interests. Harm, therefore, consists of 'the thwarting, setting back, or defeating of an interest.'[31] What, then, is an interest?

It is perhaps useful to locate Feinberg's seminal contribution to legal theory within the context of the evolution of consequentialist thought. The tradition of evaluating actions in terms of their effects upon people was already long established before the notion of harms and interests (arguably) became the dominant concepts in consequentialist thought. In the essay entitled 'Utilitarianism', Mill contended

> that pleasure, and freedom from pain, are the only things desirable as ends; and that all desirable things (which are as numerous in the utilitarian as in any other scheme) are desirable either for the pleasure inherent in themselves, or as means to the promotion of pleasure and the prevention of pain.[32]

Although, at the outset of *Harm to Others*, Feinberg openly acknowledged his intellectual debt to Mill, he completely rejected this notion of 'mental state' utilitarianism, the view that the aim of morality is to promote some kind of subjectively pleasurable states of mind.[33] Rather, Feinberg's approach added and relied upon the concept of 'interests', closely related to, but distinct from, 'wants' or

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[29] Id.
[30] For a contrary view, according to which a certain variety of interests can meaningfully be attributed to inanimate objects, see Tom Regan 'Feinberg on What Sorts of Beings Can Have Rights' *The Southern Journal of Philosophy* (1976); 14: 485-498.
[31] Ibid, at p.33.
[32] J.S.Mill, 'Utilitarianism', in Warnock, ed. Utilitarianism, op cit, at p.257
[33] Feinberg, *Harm to Others*, op. cit., at p.85.

'desires'. (Feinberg had earlier explained the relationship as being of the nature that 'desires or wants are the materials interests are made of.'[34]) 'A person has an interest in Y,' he claimed, 'when he has a *stake* in *Y*, that is, when he stands to gain or lose depending on the condition or outcome of *Y*.'[35] If this definition is accepted, then the connection with wants becomes apparent. It may, after all, be difficult to see how a person could be said to 'gain' or 'lose' save by making reference to what he actually wants.

Feinberg certainly accepted this in relation to what he refers to as 'ulterior' interests.[36] However, he did not hold this to be true for that class of interests which he called 'welfare' interests, that is, that class of minimum interests such as 'health, economic sufficiency, emotional stability [and] political liberty',[37] the fulfilment of which are necessary for the fulfilment of all other interests.[38] As regards these welfare interests, Feinberg took the view 'that what promotes them is good for a person *in any case*, whatever his beliefs or wants may be.'[39]

It is difficult to disagree with the claim that a certain minimum standard of health is likely to be a prerequisite of most other interests; an individual may not care very much about his health for its own sake, but will require to be in moderately good health if he is to act on his desire to visit Paris or make a parachute jump. This would be an example of an interest which is linked to wants, but at one remove; the person does not want X for itself, but will require to have X if he is to achieve Y, which he *does* want. This idea will be explored more fully below. More generally, it

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[34] Feinberg, 'Rights of Animals and Unborn Generations', in *Rights, Justice, and the Bounds of Liberty*, Princeton University Press, 1980, at p.169.
[35] Feinberg, *Rights, Justice, and the Bounds of Liberty*, op. cit., at p.45.
[36] '[I]t is difficult at best to explain how a person could have a direct stake in certain developments without recourse to his wants and goals.' *Harm to Others*, Oxford University Press, 1994, at p.42.
[37] Ibid, at p.41.
[38] The concept of 'welfare interests' has also been postulated by Goodin. He defines them as 'that set of generalized resources that will be necessary for people to have before pursuing any of the more particular preferences that they might happen to have' - Goodin lists '[h]ealth, money, shelter [and] sustenance' as examples. The essence of welfare utilitarianism, according to Goodin, lies in a recognition of the fact that the majority of preferences are formed in circumstances far removed from what he refers to as an 'ideal choice situation', that is to say, a situation 'characterized by perfect information, strong will, settled preferences, and such like.' This being so, a number of those preferences expressed by persons will have failed to take account of their welfare interests; in such a situation, 'welfare utilitarianism would suppress short-sighted preference satisfaction in favour of protecting people's long-term welfare interests.'
[39] Ibid, at p.42.

may be that health can be seen as a desire in itself; as Ruth Chadwick has commented, 'it might be possible to construe all claims for medical help in terms of a desire, e.g. the desire to be well.'[40]

For the time being, it is submitted that, while almost all persons may be supposed to have interests which are bound up to some extent with health, for example, this interest is not entirely independent of their wants. Certainly, some scepticism must be expressed as to the claim that *anything* could be said to be in the interest of all persons in all circumstances.

2.2.3 *Taking* an interest and *having* an interest

There are, as was submitted above, undoubtedly circumstances in which individuals may be said to have interests which do not correspond exactly with wants. An obvious example is the scenario wherein an individual is unaware of the existence of certain factors which will have a significant bearing upon certain wants which he does harbour, or where he is unaware of the relationship of these factors to his wants.

A is going about his daily business, blissfully unaware of the fact that B has been offered a substantial sum of money to kill him. B, although he is desperate for the money, is wracked with indecision about whether or not to carry out the contract; as well as *wanting* the money, he also *wants* to comply with his moral beliefs, which tell him that killing is wrong, at least in circumstances such as these, and he also *wants* to be free from the feelings of guilt which he suspects may trouble him if he kills A. In view of the fact that A is not aware of B's existence, still less of the moral quandary with which he is faced, one could not truthfully say that A *wants* or *desires* or *would prefer* B to choose not to kill him. Quite simply, he has no view on the subject at all. However, A has a whole range of wants and desires which will be frustrated if B kills him before he has a chance to fulfil them. There are friends he wants to see again, books he wants to read, and myriad other ambitions, great and small, which he will be denied the opportunity to achieve if his life is ended now. It would therefore be

[40] Ruth Chadwick, 'Having Children: Introduction' from her collection *Ethics, Reproduction and Genetic Control*, Routledge, 1990, at p.18.

completely wrong to say that the outcome of B's decision is of no consequence to A.[41]

In situations such as these, where the likelihood of someone's desires being satisfied is affected by decisions or action about which he knows nothing, a person may be said to have an interest in that decision, even though he has no desires or preferences corresponding directly to it. As Mary Anne Warren has said:

> Non-self-aware beings may not consciously *take* an interest in their own survival, but it does not follow that they cannot *have* such an interest. Having an interest in something does not require a conscious desire for it, but only the potential to experience some benefit from it.[42]

This idea of having an interest could, therefore, be extended to beings that are unaware even of the *concept* of interests, as in Warren's example:

> Thus, it seems plausible that if a spider has an interest in anything, then it has an interest in not being smashed flat – even if the process is quite painless. Because continued life is necessary for the spider's future enjoyment of whatever pleasures it has enjoyed in the past, it seems obvious that it has an interest in survival.[43]

Certainly, a spider is unlikely to possess the requisite reflective capacities to enable it to *take an* interest in its continued survival – existential musing almost certainly requires a more sophisticated brain. But implicit in Warren's contention is that the spider possesses *some* interests, even if it is not consciously aware of possessing them. Were it not capable even of enjoying basic sensual pleasures, it is difficult to see what interests would be frustrated or thwarted by its painless demise. This question of the attribution of interests to beings that are not aware, in any reflective sense, of *having* interest will be revisited in the next chapter.

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[41] James Griffin has illustrated the same thing with a slightly more prosaic example: 'if you cheat me out of an inheritance that I never expected, I might not know but still be the worse off for it.' Griffin, James. 'A Sophisticated Version of the Desire Account', in Glover, J., ed. *Utilitarianism and its Critics*, New York, Macmillan Publishing Company, 1990, at p.72.

[42] Mary Anne Warren, *Moral Status: obligations to persons and other living things*, Oxford, Oxford University Press, 1997, at p80

[43] Id.

2.2.4 Wants that don't qualify as interests

Just as Feinberg saw some interests existing independently of wants, so too did he recognise the possibility of wants existing without giving rise to interests, contending that 'it does not seem likely that wants, even strong wants, are *sufficient* to create interests.'[44] If this view were taken, it would follow that not all instances of frustrated wants lead to 'harms.' Indeed, Feinberg states this quite explicitly, opining that '[w]e are commonly enough disappointed, dissatisfied, even frustrated, without suffering harm.'[45] He cites the example of a baseball fan, who *wants* his team to do well, but who - according to Feinberg - has not 'invested so much of a psychic stake in the outcome of a season's play'[46] to qualify as having an *interest* bound up with his teams fortunes.

Objections could be levied at this claim on purely empirical, psychological grounds - for many, particularly those from the lower socio-economic groups, sport plays a major role in their lives. They take a pride, albeit a vicarious pride, in the achievements of their football team or a local boxer, when their circumstances are such as to deny them this in any more direct way.

It may further be seen that this distinction between wants which lead to interests (and therefore, conceivably, harms), and those which do not, can seem rather arbitrary and difficult to sustain. Feinberg refers to various categories of unpleasant experience – 'hurts' and 'offences', for example - which frustrate wants, but do not, according to him, harm interests. Certainly, there are *quantitative* distinctions to be made between wants of varying intensities, and between wants of varying degrees of permanence or transience. Yet it is difficult to see why wants of varying degrees of intensity, duration and stability should not be taken to give rise to *interests* which also vary in these respects. It is not immediately obvious, for example, why a 'mere "passing desire," however genuine or intense, does not establish an interest.'[47] Nor is it evident, in the absence of any clear criteria, how a decision would be made as to whether a want is of sufficient permanence to give rise to an interest.

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[44] Ibid, at p.43.
[45] Id.
[46] Id.
[47] Ibid, at p.55.

2.2.5 Harms of omission?

Is the definition of 'harm' to be limited to positive acts which set back interests, or can omissions also qualify as harms? This question is of great importance to anyone interested in the limits which the Harm Principle sets on legislative interventions in the liberty of individuals, not least because, were the former premise to be accepted, this would appear to curtail significantly the legislature's ability to raise taxes or otherwise pursue social welfare, far less redistributive policies. If 'harm' is to be construed in the narrow sense of rendering someone's condition worse, then it is possible to argue that, when the state fails to provide universal access to education or healthcare, it does no harm; that failure, after all, did not *worsen* the condition of those who are already without those services.

Holtug argues that 'It would seem that in order for a person to be harmed by some event, her life must go worse because of it.'[48] Yet far from settling the question of omissions, this raises the further question 'worse than what?' Is harm to be defined solely in terms of the position immediately prior to the purportedly harmful act/omission? The difficulties presented by such an analysis are illustrated by the following scenario:

> Suppose a person's pain would have gone away, had I not acted to ensure that it continues. Clearly, I harm him, despite the fact that I leave him in no more pain than he was prior to my intervention.[49]

Holtug considers the possibility of adopting a 'normal' condition, relative to which the person's condition after the relevant event could be assessed, but notes that this would scarcely assist the person who has always, or ordinarily, been in pain. Instead, he opts for a comparison with a 'counterfactual baseline', that is, a comparison with 'a person's situation, had the putatively harmful event not taken place.'[50] Thus, an act which prevents the fulfilment of an interest can be described as harmful, even though

[48] Nils Holtug, 'The Harm Principle', *Ethical Theory and Moral Practice*, (2002); 5: 357-389, at p 364.
[49] Ibid, at p368
[50] Ibid, at p369

that interest is no more unfulfilled than it was before the act. The relevant test is what would have happened 'but for' the act.

Holtug's counterfactual baseline, then, extends the definition of harm to acts which prevent improvement in, as well as those which actually worsen, someone's situation. This, however, seems still to limit our account of harm to positive acts; the question of 'harmful omissions' remains troublesome in the face of the difficulty in conceptualising how an omission might *prevent* anything.

Feinberg spends some time on this vexing issue,[51] concluding ultimately that omissions can indeed be harmful, when they prevent someone acquiring or attaining not only what they *would* have done otherwise, but that for which they had a legitimate expectation. For Feinberg, the all-important distinction is between a harmful omission and a mere failure to confer gratuitous benefit, a distinction that depends upon whether the alleged harmer owed a duty to the other party. Duties can be incurred voluntarily, as when we make a promise to another, but for Feinberg, some duties to benefit, or to prevent harm, exist irrespective of what we have agreed to do:

> The good swimmer on the bridge who watches a stranger drown in the water below has inflicted a harm, and a grievous one, by his omission (the common law notwithstanding); and this is so not only because death is the sort of thing we regard as harm whatever its cause, but also because the victim has a right to the assistance of the stranger, and the stranger had a correlative duty to save him. Merely being a fellow human being is enough to ground a duty when the threatened harm is that severe.[52]

A similar conclusion is arrived at by Joseph Raz:

> Sometimes failing to improve the situation of another is harming him. One can harm another by denying him what is due to him. This is obscured by the common misconception which confines harming a person to acting in a way which results in that person being worse off after the action than he was before. While such actions do indeed harm, so do acts or omissions the result of which is that *a person is worse off after them than he should then be*. One harms another by failing in one's duty to him,

[51] The chapter on Failures to Prevent Harm is the longest in Volume 1 of *The Moral Limits of the Criminal Law*; see Feinberg, *Harm to Others*, op. cit., pp.126-187.
[52] Feinberg, *Harm to Others*, op. cit., at p140

> even though this is a duty to improve his situation and the failure does not leave him worse off than he was before.[53]

If the Harm Principle can recognise positive duties to prevent harm, as well as negative duties to avoid its infliction, then it is easy to see how this can have potentially important implications for the application of that principle to the Genetic Supermarket thesis. If prospective parents (or anyone else) owe positive duties to improve the condition of their future or actual children, then this may well curtail the range of choices available to them to a greater extent than if their duties were merely to avoid making matters worse than they already were. However, as I will explore in the next chapter, the question of 'worse than what?' is one which emerges again within the context of such decisions.

2.2.6 Harms and wrongs

Feinberg's approach does not hold that any harmful conduct can justifiably be curtailed by the criminal law. Later in this chapter, I will discuss the important *de minimis* restriction, but it is also important to realise that some non-trivially harmful conduct cannot, on Feinberg's conception, by constrained by law. He has argued, for example, 'no plausibly interpreted harm principle' would justify the prohibition of, for example, 'setbacks to interest incurred in legitimate competition or harms to the risk of which the "victim" freely consented.' Rather, 'only setbacks of interests that are wrongs ... are to count as harms in the appropriate sense.'[54]

How, then, does Feinberg define a 'wrong'? This he explains by reference to 'established priority rankings' of potentially competing interests:

> The interests of different persons are constantly and unavoidably in conflict, so that any legal system determined to "minimize harm" must incorporate judgments of the comparative importance of interests of different kinds so that it can pronounce "unjustified" the invasion of one person's interest of high priority done to protect another person's interest of low priority. Legal wrongs then will be invasions of interests which violate established priority rankings.[55]

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[53] Joseph Raz, *The Morality of Freedom*, Oxford, Clarendon Press, 1986, at pp415-416, emphasis added.
[54] Feinberg, *Harm to Others*, op. cit., at p36
[55] Feinberg, *Harm to Others*, op. cit., at p35.

Criminal prohibition, then, is only justified when the conduct in question interferes with an interest deemed in advance to be of high priority. Later in this chapter, I will advance the proposition that the interest in reproductive liberty should be accorded just such a status, and that interferences with it will usually, on Feinberg's analysis, constitute both harms and wrongs.

Although Feinberg's work is probably the most influential in the ethics of harm and interests, his definitions and explanations have not gone unchallenged. Bioethicist John Harris has proposed an alternative account of 'harms' and 'wrongs', and of the relationship between them. Harris begins by seeking to identify the common ground he shares with Feinberg:

> A condition that is harmful, Feinberg and I would agree, is one in which the individual is disabled or suffering in some way or in which his interests or rights are frustrated.[56]

However, even this early in his commentary, Harris has created difficulties for himself, or at least for his readers, by virtue of some uncharacteristically careless use of language. First, this does not seem entirely to accord with Feinberg's definition of a *harmful*, as opposed to a *harmed*, condition. For Feinberg, a harmful condition is one likely to give rise to further, future harms:

> A *harmed* condition of a person may or may not also be a *harmful* condition, depending on whether it has itself the tendency to generate further harm. A blistered finger may be to some small degree a harmed condition, but unless the finger is on the hand of a concert pianist or a baseball pitcher, it may not be at all harmful.[57]

Secondly, Harris is equally careless in his use of language when he claims that Feinberg would agree that a harmful (or harmed) condition is one in which the individual's 'interests *or rights* are frustrated'. A situation which sees someone's rights frustrated – perhaps 'infringed' or 'violated' are more apt verbs – would for Feinberg, constitute a 'wrong', but need not involve a harm; indeed, he specifically acknowledges the possibility of 'harmless wronging'.[58]

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[56] John Harris, *Wonderwoman and Superman*, op. cit., at p88.
[57] Feinberg, *Harm to* Others, op. cit., at p.31.
[58] Feinberg, *Harmless Wrongdoing*, op. cit.

In large part, the essence of Harris's disagreement with Feinberg lies in his contention that is possible to be harmed without being rendered worse off. He offers this example:

> When in the First World War soldiers deliberately shot themselves in the foot, or injured themselves in some other way so as to get what was called a 'Blighty Wound', one that would get them sent home to 'Blighty', and out of the fighting, they were guilty of an act of deliberate self-harming. Indeed were it not an act of self-harming, which may have disabled or handicapped the individual to some extent, it would not have secured the desired effect. ... Insistence on tying harm to the idea of being made 'worse off' deprives us of the ability to characterise what is going on here as a self-interested act of harming. It is surely clearer and more consistent with what we wish to say in such cases to describe the acts of these soldiers as acts of self-harming but by which they did not wrong themselves.[59]

In a sense, Harris is undoubtedly correct when he claims that the soldiers 'harmed' themselves; there is no question that they did indeed set back some of their own interests, interests in avoiding extreme pain and possible disability, and perhaps interests in being suspected of, or even executed for, cowardice. However, if any act that sets back *any* interests whatever were to be regarded as a harm for the purposes of the Harm Principle, then it would seem that the range of justifiably prohibited behaviours would be very wide indeed. For as discussed elsewhere in this chapter, it is possible to find in almost any act an interest somewhere, however trivial, that is thwarted or frustrated. Most troublingly, acts that clearly benefit an individual by promoting some of his most important interests in important ways will often involve the setting back of some other of his interests. (To take an obvious example, life-saving heart surgery on someone who wants desperately to avoid death would be universally considered a benefit, but there is no question that such surgery sets back that person's interests in avoiding pain and a prolonged period of infirmity while she recovers.)

By claiming that the soldiers *harmed*, but did not *wrong*, themselves, it seems perhaps as if Harris's principal disagreement with Feinberg is not in his definition of

[59] Harris, *Wonderwoman and Superman*, op. cit., at p92

'harm', but rather his definition of 'wrong'. For Harris, it would seem, a wrong occurs when someone sustains a balance of harms over benefits. Thus, the soldiers are not wronged because their more important interests in avoiding early death are furthered, but are nonetheless harmed because their (relatively unimportant) interests in avoiding pain and disability are set back.

As will become clear in the next chapter, this is an issue of particular importance for consideration of PGD, particularly in relation to what has become known as the Non-Identity Problem, and it will be explored in greater detail there. For the moment, it will suffice to say that a distinction can be drawn between harms *per se* and harms *on balance*. Such a distinction would allow us to say, with Harris, that a soldier harmed himself when he shot himself in the foot, but that in so doing he sustained a net balance of benefits over harms. Assuming the wound has the desired effect, and he does not end up succumbing to gangrene or before a firing squad, in the overall reckoning, he was made better off than he would have been but for the injury; thus, he is not harmed on balance.

> There *can* be wrongs that are not harms *on balance*, but there are few wrongs that are not *to some extent* harms. Even in the most persuasive counterexamples, the wrong will usually be an invasion of the interest in liberty.[60]

2.3 The Harm Principle

While the concept of harm is likely to be of some relevance to most of those with an interest in bioethics, it occupies a unique position for adherents to the Harm Principle, for whom the presence and magnitude of harm alone are determinative of whether legal regulation is justifiable. This approach originated in the writings of John Stuart Mill, but attained more contemporary prominence thanks largely to the writings of H.L.A. Hart, Joel Feinberg and Joseph Raz.

Designating a starting point for any school of thought is inevitably a rather arbitrary business. No idea, however revolutionary, springs into being *ex nihilo*, uninfluenced by that which came before. In identifying the two seminal works of John Stuart Mill

[60] Feinberg, *Harm to Others*, op. cit., at p35

– respectively *On Liberty* (1859) and *Utilitarianism* (1861) – as the central texts of the Harm Principle, I do not seek to assert that respect for the liberty or autonomy or freedom of the individual was an unknown notion until it was dreamt of in mid-Nineteenth Century England. Both of the central elements of Mill's philosophy were derived from other writers and traditions. The freedom of men 'to order their actions and dispose of their possessions and persons as they see fit ... without asking leave or dependency upon the will of any other man' had been central to John Locke's writings almost two centuries before Mill produced his most famous works.[61] For Locke, the only justifiable restriction on this freedom was imposed by the 'law of nature', which included that 'no one ought to harm another in his life, health, liberty, or possessions' – a limitation that clearly found its echoes in Mill's work.

It is clear, however, that in terms of influence upon the discourse of harm in the twentieth century, Mill's influence was unparalleled. Indeed, almost every contemporary writer concerned with such notions makes some reference to Mill.[62] In probably his most renowned essay, 'On Liberty', he set out a position that, while purportedly flowing logically from Benthamite utilitarianism, seems to many observers to have departed substantially from it.[63] Mill used this, probably his most impassioned work, to rail against 'the tyranny of the majority',[64] claiming that 'there is a limit to the legitimate interference of collective opinion with individual independence ...'[65] In the essay's best known passage, Mill set out a theory with regard to the extent of this 'legitimate interference':

> the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant.[66]

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[61] John Locke, *Two Treatises of Government*, ed. Peter Laslett, New York, Cambridge University Press, 1967
[62] See Feinberg, *Harm to Others*, at (inter alia) pp.3-4, 11-15, 115-116; Harris, *Wonderwoman and Superman*, at p52 and p83; Warren, *Moral Status*, at p64;
[63] See H. L. A. Hart, 'Natural Rights: Bentham and John Stuart Mill', in *Essays on Bentham: Jurisprudence and Political Theory*, Oxford, Clarendon Press, 1982, at pp.102-103. For others contended points of departure between Mill and his utilitarian predecessors, see Neil Thornton's *The Problem of Liberalism in the Thought of John Stuart Mill*, London, Garland Publishing Inc., 1987.
[64] 'On Liberty', op. cit., at p.129
[65] Ibid, at p.130

Whether Mill's belief in liberty really derived, as he sometimes contended,[67] from an empirical belief that it was always the best route to happiness, or whether he was (perhaps unconsciously) importing a principle extrinsic to traditional utilitarianism,[68] remains a moot point. It may be the case that he was branching out into a primitive form of 'rule utilitarianism', whereby he recognised that individual cases might arise wherein the greatest happiness could be maximised by curtailing individual liberty even in purely 'self-regarding' areas of life, but felt that respecting a rule that protected those areas from encroachment by others would promote the best outcome in the majority of cases.[69]

What is clear is that he was the first to wed the two concepts that together form the Harm Principle; respectively, the ethical principles of respecting individual liberty and protecting others from harm. In this, Mill brought about a radical change to the utilitarianism of Godwin, Bentham and James Mill, a change Mary Warnock maintains 'without which it might well have been too rigid and narrow to survive.'[70]

The evolution of utilitarianism, liberalism and the Harm Principle in the Twentieth Century in reality commenced about midway through that epoch. For a variety of reasons that will not be explored here, philosophy in the early 1900s came to be focused on areas other than the normative discipline of Bentham and Mill; one commentator has referred somewhat scathingly to an academic tendency that 'reduced the once vigorous normative discipline into a linguistic game.'[71]

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[66] Ibid, at p.135

[67] Ibid, at pp.206-207.

[68] Hart contended that the liberty principle, 'with its one exception is therefore, for Mill, a constraint on the pursuit of aggregate welfare at the cost of individuals and not merely an indirect way of securing it.' 'Natural Rights: Bentham and John Stuart Mill', op cit, at p.103.

[69] Anne Maclean has certainly taken this view: 'We have seen that according to Mill the Principle of Utility is the "first" or "fundamental" principle of morality. He affirms, however, the practical necessity of "secondary principles" - derivative moral principles or rules by means of which, for the most part, moral judgements must be made in particular cases. These constitute the rules of rule utilitarianism. The point that must be emphasised is that on Mill's account secondary principles all derive their authority from the Principle of Utility; this principle alone, he insists, is the ultimate standard of right and wrong.' *The Elimination of Morality: Reflections on Utilitarianism and Bioethics*, London, Routledge, 1993, at p.10.

[70] Mary Warnock, 'Introduction to Utilitarianism', op cit., at p.9.

[71] Matti Häyry, *Liberal Utilitarianism and Applied Ethics*, op. cit., p.45

The 1950s and 1960s saw a revival in interest in utilitarian theories, with debates about, inter alia, the respective merits of 'act' and 'rule' utilitarianism, and of 'average' and 'total' utilitarianism, attaining prominence in academic discourse.[72] From the perspective of the Harm Principle, however, perhaps the next significant milestone was the publication in 1959 of the Report of the Committee on Homosexual Offences and Prostitution, immortalised in the study of contemporary ethics as the Wolfenden Report[73].

Enough has been written on the deliberations and conclusions of the Wolfendon Committee, and in particular on the legendary debate between Patrick Devlin and Professor H. L. A. Hart, to obviate the need for much further discussion here.[74] However, Hart's arguments to the Committee, subsequently popularised in his series of lectures at Stanford University and collected in *Law, Liberty and Morality*,[75] revived interest in the Millian argument that individual liberty is not lightly to be interfered with.

In particular, Hart's contribution to the debate on sexual offences saw him adopt a stance against what he referred to as 'legal moralism' - the notion, propounded by (among others) Patrick Devlin, that an individual may be punished for conduct which, while causing no harm, transgresses against the moral norms of his society. Hart's antipathy to this doctrine is unambiguous:

> The idea that we may punish offenders against a moral code, not to prevent harm or suffering or even the repetition of the offence but simply as a means of venting or emphatically expressing moral condemnation, is uncomfortably close to human sacrifice as an expression of religious worship.[76]

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[72] 'An outline of a system of utilitarian ethics', first published in 1961 but available in J. J. C. Smart and Bernard Williams, *Utilitarianism For And Against*, Cambridge University Press, 1973, contains overviews of these and other debates within utilitarian philosophy.

[73] Committee on Homosexual Offenses and Prostitution, 1957. *Report of the Committee on Homosexual Offenses and Prostitution.* London: Her Majesty's Stationery Office.

[74] See, for example, Burton M. Leiser, *Liberty, Justice, and Morals: Contemporary Value Conflicts*, Second Edition, New York, MacMillan Publishing Co., Inc., 1979, pp.10-19; Gerald J. Postema, 'Public Faces – Private Places: Liberalism and the Enforcement of Morality', in Gerald Dworkin, ed. *Morality, Harm, and the Law*, Oxford, Westview Press, 1994, pp. 76-90; Jeffrie G. Murphy 'Legal Moralism and Liberalism' (1995) 37 *Arizona Law Review* 73-93.

[75] *Law, Liberty, and Morality*. Oxford, Oxford University Press, 1963.

[76] Ibid, at pp.65-66.

Hart, it must be made clear, was far from a slavish disciple of Mill, a fact that he makes clear early in the book. In particular, he rejected the strong Millian claim that the protection of others was the sole justification for interference with liberty: 'for I myself think there may be grounds justifying the legal coercion of the individual other than the prevention of harm to others.'[77] Hart's disagreement from Mill on this point, however, can be read as consistent with the utilitarian axioms to which Mill purported to adhere. In particular, Hart questioned the empirical premises upon which Mill's views of liberty were founded:

> Underlying Mill's extreme fear of paternalism there perhaps is a conception of what a normal human being is like which now seems not to correspond to the facts.[78]

His departures from the Millian line notwithstanding, Hart's work at this time propelled the notion of the Harm Principle back to the forefront of discussions about the role of the state and of the law. In particular, his antagonism to the concept of 'legal moralism' carried significant echoes of Mill, and may have been influential in the decriminalisation of certain of the sexual offences that the Wolfenden Committee was established to discuss.

Although Hart's contribution to the philosophy of law encompassed a far wider territory than that explored here, including, inter alia, questions of the existence of natural rights,[79] whether and when there is a duty to obey the law,[80] legal responsibility and the justification of punishment,[81] his contribution to the Harm Principle is probably that for which he will most widely be remembered.

While the origins of the Harm Principle lie in England, in the latter part of the Twentieth Century it assumed a more international dimension, through legal theorists, Joel Feinberg and Joseph Raz. Both took Mill's basic statement as their starting point, but went on to interpret and refine the principle in different ways. Raz, for example, sought to extend Mill's dictum so as to add harm to the actor

[77] Ibid, at p.5.
[78] Ibid, at pp.31-32.
[79] 'Are there any Natural Rights?', *Philosophical Review* 64 (1955): 175-191.
[80] 'Legal and Moral Obligation', in A. I. Melden, ed. *Essays in Moral Philosophy*, Seattle, University of Washington Press, 1958.

himself as a 'justifiable ground for coercive interference with a person',[82] while Feinberg's work imported the concept of 'interests' into the notion of harm. Both, however, subscribed to the view that the prevention of harm was the only justifiable ground for state coercion.[83]

2.3.1 Harm and liberty

The question at the heart of this thesis can be formulated in one of two ways. The 'positive' formulation asks whether prospective parents should be permitted to avail themselves of the technology of Preimplantation Genetic Diagnosis (PGD) in a manner that would give effect to Nozick's conception of the Genetic Supermarket, i.e., free from intervention by the law. The 'negative' formulation, on the other hand, turns this around and enquires whether the state is justified in imposing restrictions on the use of PGD, in restricting access to this Genetic Supermarket.

From a purely linguistic view, it might be thought that these are merely two ways of phrasing the same question. On closer examination, however, it seems that the direction from which we approach this question is a matter of more than grammatical significance. Whether the question is asked in the 'positive' or 'negative' form says rather a lot about the way in which it will be approached, and in particular, about where the burden of justification will lie. Should prospective users of the Genetic Supermarket be expected to justify their choices (as well as the right to make those choices), or should that onus will lie with those who would restrict those choices?

The significance of this question should become apparent when consideration is given to the necessity of a default position; what should happen if neither party is able to make out a satisfactory case? As this chapter will show, a liberal default position would hold that, absent a convincing case to the contrary, those who wish to use PGD should be at liberty to do so. As subsequent chapters will show, however, this is not how the regulation of reproductive technologies in the United Kingdom actually occurs. Rather, it is not uncommonly the case that a restrictive default

[81] 'Intention and Punishment', *Oxford Review* 4 (1967): 5-22; *Punishment and Responsibility: Essays in the Philosophy of Law*, Oxford, Clarendon Press, 1968.
[82] Joseph Raz, *The Morality of Freedom*, op. cit., at p413.
[83] See Raz, Chapter 15, particularly pages 400, 413, 419, and Feinberg at pages 11-12 and 15.

position is adopted, with the onus lying firmly with those seeking an exception to justify that exception.

(Consider, for example, the HFEA's guidelines on the use of PGD for human leukocyte antigen typing, a technology that allowed Raj and Shahana Hashmi to maximise the chances of giving birth to a child that would be a viable donor for their existing child. This case, and the HFEA's response thereto, will be considered in Chapter 5.)

For adherents to the Harm Principle, the default presumption will be one of liberty, that is, a presumption that the onus lies with those who would impose restrictions on the liberty of (at least competent adult) individuals. Of course, many people – ethicists and otherwise – would regard liberty as intrinsically valuable,[84] but it is possible to construct a defence of the liberty presumption without straying outwith the discourse of harm/interests. Mill, as we have seen, defended this presumption on largely empirical grounds arguing that, as a matter of fact, 'Mankind are greater gainers by suffering each other to live as seems good to themselves, than by compelling each to live as seems good to the rest.'[85] In particular, he sought to portray liberty as being the most efficient means of promoting happiness, noting first that each agent is

> the person most interested in his own well-being: the interest which any other person, except in cases of strong personal attachment, can have in it, is trifling, compared with that which he himself has;[86]

and secondly, that

> with respect to his own feelings and circumstances, the most ordinary man or woman has means of knowledge immeasurably surpassing those that can be possessed by any one else.[87]

[84] Beauchamp & Childress, *Principles of Biomedical Ethics*, op. cit.
[85] 'On Liberty', op. cit., at p.138
[86] Ibid, at p.206. This sentiment has been recently restated in a markedly different context, by economist Michael Albert: 'we are all the world's foremost expert in our own preferences.' *Revolution Based on Reason Not Faith or Fantasy*, 18 December 2003, published on Znet at http://www.zmag.org/content/showarticle.cfm?SectionID=41&ItemID=4710.
[87] 'On Liberty', op. cit., at pp.206-7

Although Mill's Benthamite language would be unlikely to appeal to modern day 'interests advocates' like Feinberg and Raz, the notion that the most efficient means of furthering interests is by allowing individuals to conduct their affairs and determine their priorities as they see fit may nonetheless, in many cases, be thought a reasonable strategy for promoting interests and avoiding harms. And while we may agree with Gerald Dworkin that respecting liberty on the grounds that it actually *does* promote the interests of individuals 'is always a contingent question that may be returned by the evidence',[88] a presumption that this is ordinarily the case will place the onus upon those who would interfere with liberty to make out a harm-based case for doing so.

From this assumption flows the conclusion that allowing an individual to make his own choices is ordinarily the best means of promoting the best consequences *for him*. It says nothing, of course, about whether this is likely to promote the best aggregate outcome for all those affected by his decision, into whose minds he can see and whose interests he cares about no more than the benevolent legislator. However, the point is precisely that the assumption of enlightened self-interest says *nothing* about the likely impact on others, while it says something *positive* about the consequences for the agent himself. A positive that is not countered by any resulting negative leads to a net gain. Hence, the individual should be permitted to decide for himself in all matters *unless and until* it can be shown that his actions are likely to have detrimental effects for others. If that can be shown, then a decision must be made about whether the detrimental effect for others outweighs, or is outweighed by, the beneficial consequences for the actor himself. Such a balancing of interests may be difficult, but the point remains that, unless some likely harm to other parties can be shown, the most likely course of action to maximise good outcomes lies in respecting liberty.

There is, in addition, another strand of the argument in favour of a liberty presumption. This asserts that, as well as being the course of action most likely to further the agent's other interests, the very fact of interfering with liberty invariably frustrates an interest in itself. This derives from the belief that we each have an

[88] Gerald Dworkin, 'Paternalism', from *Philosophy of Law*, ed. Feinberg and Gross; Wadsworth Publishing Company, 1995, at p.209.

interest in having our own choices respected, irrespective of any consequences that flow therefrom. The Liberty Presumption may be based partly upon the 'greater likelihood of this bringing about outcomes we find satisfactory in other ways.'[89] However, when considering how much weight to attach to the principle of respect for liberty, we must also bear in mind the desire harboured by most persons to make decisions for themselves. According to utilitarian philosopher Jonathan Glover, this desire for self-determination must in itself be accorded substantial weight in any utilitarian calculus, independent of the fact that respecting liberty is likely to lead to the maximum satisfaction of other desires: 'a desire so important to us would unavoidably be given a central role in any utilitarianism centred around people's desires and preferences.'[90]

On this view, when we deprive the reckless investor of the ability to decide how to spend his money, or when we take from the poor judge of character the freedom to choose her own relationships, we deprive them of something valuable *even if* the choices we make on their behalf lead to better outcomes for them than the choices they would probably have made for themselves; we deprive them of the knowledge that, however good or bad their life choices, they remain *their* life choices.

We therefore have two harm-based reasons for respecting liberty: first, the belief that, in practice, the best means of furthering future interests and avoiding future harms in individual cases is by allowing individuals to choose for themselves; and second, the belief that there is harm inherent in any interference with liberty, regardless of the future consequences of so doing. Taken together, these beliefs give rise to a presumption in favour of respecting liberty. Like all presumptions, this is open to rebuttal, whether by showing that the Millian presumption is untrue in a particular case, or by showing that any harm we inflict upon the individual when we interfere with his liberty is outweighed by harm avoided to (or benefit bestowed upon) other parties. But the onus of rebuttal lies squarely with those who would restrict, obstruct or criminalise, rather than with those who would avail themselves of individual choice.

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[89] Jonathan Glover, *Causing Death and Saving Lives*, London, Penguin Books, 1990, at p.80.
[90] Ibid, at p.81.

2.3.2 The *de minimis* rule

A criticism frequently levied at the Harm Principle is that it sets the threshold for interference with liberty too low. As Holtug has claimed:

> it is very seldom that an individual's behaviour does not affect others. And if all effects that are negative for some person qualify as harm, then it seems that the Harm Principle offers at best inadequate protection of individual liberty.[91]

Feinberg attempted to circumvent this problem of the 'ubiquity of harm' by defining harm so as to exclude certain adverse effects; 'offences' and 'hurts', for example, did not qualify as 'harms', while some wants did not give rise to interests, and hence would not give rise to harms when they were frustrated. I have already expressed some concern about the apparent arbitrariness of such designation, but it is also worth considering the (perhaps even greater) danger that lawmakers would draw lines in a non-arbitrary but self-interested manner, excluding from the category of 'harms' those adverse outcomes that actually furthered their own interests.

Fortunately for the Harm Principle, Feinberg's response to the sort of criticism levied by Holtug does not rely on excluding certain categories of wants. There are two other strands to his approach that limit the legitimate interference of the law with individual liberty: the first contending that not all acts that cause 'harms' also involve 'wrongs', and the second that even when an act involves both a harm and a wrong, it may not be of sufficient magnitude to warrant legal intervention.

The former criterion, that in order to satisfy the Harm Principle an act must be a 'wrong' as well as a 'harm', has already been considered. The latter criterion, meanwhile, derives from the recognition that interference with liberty is itself harmful in no small measure. In the preceding section, the essence of the liberty presumption was shown to lie in the recognition that (1) when an individual's liberty is curtailed, his interests are always harmed to some extent (because of the interest in choosing for oneself), and will ordinarily suffer a balance of harm over good (because the agent him/herself will usually be the best judge of what is in his/her

[91] Holtug, 'The Harm Principle', loc.cit., at pp.363-364.

interests), and/or (2) that the intrinsic value in respecting autonomy, of which liberty is an indispensable component, will be offended against.

Given that any interference with liberty will cause some measure of harm to the person who is the subject of the restrictions, and perhaps to the intrinsic value in autonomy, it follows that any restrictions on liberty are justified only when this is necessary to prevent greater harms. Thus, Feinberg speaks of the principle that 'state interference with a citizen's behaviour tends to be morally justified when it is reasonably necessary ... to prevent harm or the unreasonable risk of harm to parties other than the person interfered with,'[92] but that in the ordinary case, 'other things being equal, [legislators] should leave individuals free to make their own choices.'[93]

The presumption in favour of liberty, then, involves more than protecting individuals from restriction purporting to be in their own best interests or in furtherance of some moral ideal disconnected from harm; it serves as a reminder that any restriction purporting to be in the interests of others also needs some justification. In the words of Feinberg, 'Liberty should be the norm; coercion always needs some special justification.'[94]

For Feinberg, this gives rise to a *de minimis* rule regarding harm. This relates to those harms which by virtue of their 'falling short of harm to the interests the law ascribes to the standard person ... are deemed to be less serious harms than those that would come from restricting the liberty of others.'[95] As Feinberg has argued, 'interference with trivia will cause more harm than it prevents,'[96] so harms must be of sufficient intensity to outweigh the interest in liberty before restrictive rules are justified to prevent them; 'Clearly, not every kind of act that causes harm to others can rightly be prohibited, but only those that cause avoidable and substantial harm.'[97]

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[92] Feinberg, *Harm to Others*, op. cit., at p.11.
[93] Ibid, at p.9.
[94] Id.
[95] Feinberg, *Harm to Others*, op. cit., at p.51.
[96] Ibid, at p.189.
[97] Ibid, at p.12

The presumption in favour of liberty does not, of course, provide any means of determining which of the competing interests is stronger; on its own, it provides no formula with which to weigh up the respective benefits and harms of a particular exercise of liberty. What it *does* involve is a recognition that the case for restriction always has an obstacle to overcome which the case for liberty does not. To take the scenario under consideration, as well as the interest of the prospective mother in having the option of PGD if she desires it, an additional factor weighs in favour of the laissez faire approach: her 'interest in having as many open options as possible'.[98]

The Harm Principle, then, can be traced back at least as far as the writings of John Stuart Mill, but the century and a half since the publication of his seminal works have seen the doctrine evolve and diverge in a variety of directions. The Benthamite concern with 'happiness' has, for the most part, given way to theories based around desires, preferences or interests. And the ground on which respect for liberty was built has shifted somewhat, with ethical pluralists such as Joel Feinberg, and Beauchamp and Childress, accepting liberty or autonomy as intrinsically, as well as instrumentally, valuable – a rejection of monistic utilitarianism about which J. S. Mill equivocated, and with which he struggled, throughout his life.

2.3.3 The interest in reproductive liberty

While writers like Feinberg and Glover have argued that there is general interest inherent in being able to choose for oneself, others have suggested that this is heightened further when the choices relate to matters particularly central to one's life plan. John Robertson has argued that reproductive liberty constitutes one such interest, and hence that it 'should enjoy presumptive primacy when conflicts about its exercise arise because control over whether one reproduces or not is central to personal identity, to dignity, and to the meaning of one's life.'[99]

Robertson adopts a liberal approach with regard to reproductive technologies, but he does not argue that reproductive liberty should always and automatically be accorded

[98] Feinberg, 'The Interest in Liberty on the Scales', op cit, at p.36.
[99] John A. Robertson, *Children of Choice: Freedom and the New Reproductive Technologies*, Princeton, New Jersey, Princeton University Press, 1994, at p24.

primacy. 'Rather, it means that those who would limit procreative choice have the burden of showing that the reproductive actions at issue would create such substantial harm that they could justifiably be limited.'[100]

Does an interest in reproductive liberty encompass decisions of the sort under consideration here? A decision to commence a pregnancy that will culminate in the birth of a severely handicapped child may well be thought to be 'central to personal identity' or 'the meaning of one's life', as would a decision to give birth to a child that will help save the life of an existing child. But could the same be said of the more 'frivolous' choices which the Genetic Supermarket would permit? Would a desire for a child of the preferred sex constitute such an important interest? For Robertson, whether a particular choice falls within the protected category

> depends on an evaluation of the importance of the choice to the parents and whether that choice plausibly falls within societal understandings of parental needs and choice in reproducing and raising children.[101]

With regard to the former, Robertson maintains that '[t]he strongest case for the parents is if they persuasively asserted that they would not reproduce unless they could select that trait, and they have a plausible explanation for that position.'[102] (This bears a close resemblance to the approach of the Court of Appeal in the tissue typing case, considered in Chapter 5). While this may seem a reasonable means of gauging the subjective importance of the decision to the potential parents, it could, if adopted, allow prospective regulators to be held hostage by those who would profess a 'this or nothing' commitment to a particular application of PGD which may, in reality, constitute something of an exaggeration. Is it really advisable, from a policy perspective, to tell those like Alan and Louise Masterton,[103] or Sharon Duchesneau and Candy McCullough,[104] that their best chance of being allowed the sort of child they want lies in an intransigent refusal to consider any other sort of child?

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[100] Id.
[101] John A. Robertson 'Extending preimplantation genetic diagnosis: medical and non-medical uses.' Comment in: J Med Ethics. 2003 Aug;29(4):213-6, at p.216
[102] Ibid, at p.215
[103] Whose desire to use PGD to ensure the birth of a girl will be considered further in Chapter 5.

As well as providing an incentive for exaggeration, such an approach might be thought somewhat unfair on parents in the position of the Hashmis and Whitakers who honestly admit that they were planning to have another child even before the possibility of a cord blood transfusion was brought to their attention;[105] would their interest in being able to have a tissue donor for Zain or Charlie be diminished merely because they wished to add to their family in any event?

Robertson's second requirement, that we consider the extent to which the choice in question 'plausibly falls within societal understandings of parental needs and choice in reproducing and raising children', is also potentially problematic, in that it seems to require that the interest is one with which 'society' would empathise. While we might reasonably expect a substantial measure of public sympathy for the efforts of the Hashmis and Whitakers, it is perhaps less likely that the majority of at least the 'non-disabled' populace would have much understanding for the efforts of a deaf couple who sought a deaf child, or a couple with achondraplasia who wanted a child with that same condition.

Yet this lack of public support need not diminish the importance of those choices for those couples. The fact that their desires are not widely shared, or understood, may reflect instead the differing experiences of disabled people in a society that, as discussed in Chapter 4, is often ignorant of their experiences and perspectives. Indeed, it may be that their perseverance with a choice that risks not only exposing them to the glare of media publicity (an experience shared by all of the couples mentioned thus far, and almost guaranteed to any future parents of 'designer babies') but seeing their choice widely denounced as irresponsible, is some evidence of the importance of that choice to them, and the strength of the interests that underlie it.

While it may be that Robertson is correct to regard the interest in reproductive liberty as being among the most central and important in most people's lives, then, I suggest that he is on less steady ground when he seeks to limit that interest to choices which command a degree of 'public understanding'. The lack of popular support for certain

[104] Whose choice a sperm donor was intended to maximise the chances that their child would be genetically deaf, and whose efforts will be considered in more depth in Chapter 3.

choices may be as likely to reflect a lack of understanding of the particular life circumstances and perspectives of those who wish to make them as a lack of important interests underlying such choices.

My starting contention, then, holds that the burden of proof lies with those who would constrain parental choice in this regard. This presumption derives from a belief that the interest in reproductive choice is a powerful one, and that any interference with it must further some interest, or prevent some harm, that is at least as great as the harm inherent in that interference. But is it really the case that a laissez faire approach to PGD will best further the interest in reproductive liberty? The centrality of this assumption to my thesis requires, perhaps, that it be tested somewhat more rigorously than it has been thus far.

2.3.4 'A silent closing': choice as harm?

The first challenge to the contention that the Genetic Supermarket furthers the interest in reproductive choice comes from those who assert that genetic counsellors and other medical professionals will to some extent impose their own views regarding PGD on their clients.[106] If such influence was shown to exist, and if it was of sufficient intensity that the 'voluntariness' of the potential parents' choices was compromised, one of the essential components of an autonomous choice - independence from controlling influences - would also be compromised. It may therefore become difficult to construct an argument claiming that this interest was furthered by a laissez faire approach to PGD.

However, for this assertion to be proven, two elements must be shown to be true: that counsellors and medical professionals *do* in fact influence their clients with their own opinions; and that this influence is *sufficient* to compromise the 'voluntariness' of the clients' decisions.

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[105] C. Hall, 'Two Cases Have Similarities and Vital Differences', *Telegraph*, 3 August 2002.

[106] Angus Clarke refers to those individuals who consult genetic counsellors as 'clients' rather than 'patients,' 'as the word "patient" would suggest that they were suffering from a disease, which is very often not the case.' Introduction to *Genetic Counselling; Practice and Principles*, ed. Angus Clarke, 1994; Routledge; London and New York.

Barbara Katz Rothman, in *The Tentative Pregnancy,* expresses scepticism as to the possibility of counsellors being genuinely non-directive: 'counselors are bound to be directive sometimes - avowedly so in some circumstances, perhaps unwittingly so in others.'[107] While recognising that 'most of them do truly value nondirectiveness,'[108] she believes that even the most well-intentioned of counsellors will inevitably find themselves influencing their clients with their own views: 'If the counselor thinks this woman sitting across from her is going to do something she will deeply regret for the rest of her life, how can she *not* influence her?'[109]

Those who are concerned about the influence of genetic counsellors upon their clients are effectively unanimous in their opinion that this influence will be favourably disposed towards making use of screening. Clarke, for example, has expressed concerns that 'clients may be subtly encouraged to take part in a programme.'[110] This encouragement may take the form of screening being represented as 'the decision of the responsible citizen ... reinforc[ing] the notion of "social responsibility in reproduction."' [111] Somewhat more subtly, it may take the form of depicting screening 'as a matter of routine, with staff clearly expecting clients to participate.'[112]

Aside from the influence allegedly brought to bear, consciously or otherwise, by counsellors and medical staff, various references have been made to other sources of influence which may conceivably cast doubt upon the notion that the availability of PGD enhances choice. Katz Rothman's research has, for example, revealed several instances of pressure from the husbands and families of pregnant women. It is interesting to note that, while the evidence of pressure from the medical profession suggests that it is almost entirely in favour of making use of genetic diagnosis, Katz Rothman's work concerning familial attitudes to amniocentesis reveals no such unanimity. 'Some women want the amnio,' she reveals, 'but their husbands "won't

[107] Barbara Katz Rothman, *The Tentative Pregnancy*, Pandora, 1994 edition, at p.41.
[108] Ibid, at p.41.
[109] Ibid, at p.47.
[110] Introduction to *Genetic Counselling: Practice and Principles*, op cit, p.18.
[111] Id.
[112] Id.

let them" have it. Others are pressured by family into having the test.'[113] Chadwick and Ngwena also speak of 'pressure from relatives to make certain reproductive decisions.'[114]

Frequent reference is also made in the literature to a source of influence which, although it lacks the immediate proximity of family, is perhaps equally powerful: prevalent attitudes within the prospective parents' (usually the concerns relate to the potential mothers) social environment. One American commentator has suggested that 'the cultural climate in the United States' may be such as to exert 'cultural pressures to select for ... highly valued traits such as intelligence or thinness,'[115] while British writers have referred to the fact that

> attitudes prevalent in society towards abortion and genetic disease may have an effect, as may the attitudes of religious or cultural groups to which counsellees belong.[116]

The extent to which this societal influence should cause concern has been considered by Kitcher. He notes that no '[i]ndividual choices are ... made in a social vacuum,' but feels that present social attitudes are such as to suggest that 'many future genetic parents ... will have to bow to social attitudes they reject and resent.'[117]

Although a handicapped neonate in the UK will not, at least in theory, be left to die due to the absence of adequate medical insurance, it has been suggested that, in a society which does not make adequate provision for the handicapped, it is misleading to speak in terms of there being a choice whether or not to make use of screening technologies. Thus it has been claimed that

> It is arguably unrealistic to suggest that people should be free to make choices about their reproductive habits, in the context of a society which places constraints on the choices available because of inadequate health and social services.[118]

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[113] Ibid, at p.42.
[114] Ruth Chadwick and Charles Ngwena 'The Development of a Normative Standard in Counselling for Genetic Disease: Ethics and Law', *Journal of Social Welfare and Family Law* (1992) 276-295, at p.284.
[115] Vicki G. Norton, 'Unnatural Selection: Nontherapeutic Preimplantation Genetic Screening and Proposed Regulation', *41 UCLA Law Review* 1581 (1994), p.1602.
[116] Chadwick and Ngwena, 'The Development of a Normative Standard ...', loc. cit., at p.284.
[117] Philip Kitcher, *The Lives To Come*, op. cit., at p.199.
[118] Chadwick and Ngwena, 'The Development of a Normative Standard ...', loc. cit., at p.282.

and that 'prenatal diagnosis cannot really be a choice when other alternatives are not available.'[119]

It is difficult to dispute the contention that having a child affected by certain conditions is likely to have a considerable impact upon the social and economic status of its parents. Certainly, it would be reasonable to expect prospective parents to have reservations about bringing a handicapped child into existence 'if there is no confidence in the willingness of society to care for their child once they are unable to do so'.[120]

Whether this fact is sufficient to bear out the contention that genetic prenatal diagnosis 'cannot really be a choice'[121] is somewhat more contentious. The nature of 'voluntariness,' and the varieties of influence which can be brought to bear, will be considered later in this chapter. For the time being, however, two observations will be made relating to the argument that the lack of societal provision for the handicapped renders the language of 'choice' inappropriate.

The first observation relates to the assertion levied by Abby Lippman, that

> [c]ontinuing a pregnancy when the fetus has been found to have Down syndrome cannot be considered a real option when society does not truly accept children with disabilities or provide assistance for their nurturance.[122]

(Once again, although this particular argument was directed at prenatal screening by amniocentesis, it is submitted that the essence of Lippman's argument would be equally valid if applied to PGD.)

The first, rather glib, observation in the face of such a suggestion would be that, while some women faced with a diagnosis of Down's syndrome do indeed elect to abort, many others choose to continue with the pregnancy, while at least some decide

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[119] Abby Lippman, 'Prenatal genetic testing and screening: constructing needs and reinforcing inequalities', in *Genetic Counselling: Principles and Practice*, from *Genetic Counselling; Practice and Principles*, ed. Angus Clarke, London, Routledge, 1994, at p.152.

[120] Angus Clarke, "Genetics, ethics, and audit", *The Lancet* 1990; 335;1146.

[121] Lippman, 'Prenatal genetic testing', loc. cit., at p.152.

[122] Abby Lippman, "The Genetic Construction of Prenatal Testing: Choice, Consent, or Conformity for Women?" from *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, ed. Rothenberg and Thomson; Ohio State University Press, 1994, at p.19.

to forego the option of amniocentesis altogether.[123] In one sense, this is surely evidence that a 'choice' exists, albeit in the crudest sense. Yet it may be that, while the prevailing societal attitudes may not be sufficiently powerful to deprive *all* women of a meaningful choice, at least *some* – perhaps those without adequate economic resources or strong networks of familial or social support – are effectively deprived of a choice.

The second observation is, perhaps, more serious for Lippman's contention. In deciding whether the availability of PGD has widened or narrowed the degree of choice which women have in relation to reproduction, it is perhaps interesting to consider what measure of choice would have been available to them had this technology never been invented. If it were really the case that those women who give birth to handicapped babies face such severe hardship that they effectively have no choice but to undergo screening, the question arises: what options would they have faced if prenatal screening (or PGD) did not exist? A woman who had already given birth to one handicapped child, or who knew from experience that a certain condition 'ran in the family,' would surely be under severe, and perhaps irresistible, pressure not to reproduce at all. This suggestion is borne out by clinical geneticist Angus Clarke, who notes that 'many women in families with Duchene muscular dystrophy ... used to fear pregnancy and chose to have few children, if any, or to terminate all male fetuses.'[124]

We might also wonder whether, if Clarke, Katz Rothman, et al, are correct in claiming that it is genuinely impossible for counsellors to avoid influencing their clients with their own opinions, a case perhaps emerges for dispensing with the facade of non-directiveness, for stating their opinions and biases explicitly. This suggestion is taken seriously by Clarke. He considers that 'non-directiveness is unattainable, and that directiveness is acceptable as long as it is explicit; unacknowledged directiveness may be much more manipulative.'[125] A similar approach has been examined by Chadwick and Ngwena, who suggest that 'it is

[123] Several examples of each choice are, in fact, represented by the women whose experiences are documented by Katz Rothman in *The Tentative Pregnancy*, op. cit.
[124] Clarke, 'Genetics, ethics, and audit', loc. cit., at p.1145.
[125] Clarke, Introduction to *Genetic Counselling: Practice and Principles*, op. cit., p.19.

perhaps a matter of candidly owning up to it [the bias in favour of directive counselling] and justifying it on the grounds of non-maleficence.'[126]

While it is possible that a combination of openness, reasoned argument and sensitivity to the client's values and priorities could ensure that counsellors do not exert such influence as to undermine voluntariness or independence from controlling influences, it is of course impossible to make the same guarantees regarding other sources of influence. With the possible exception of Angus Clarke's (presumably flippant) suggestion that all prospective mothers should attend assertiveness classes,[127] it is impossible to imagine how women could be protected from familial or societal pressures which exceeded acceptable persuasion and entered the realm of manipulation, or even coercion.

It does not automatically follow, however, that these influences are sufficient to undermine the voluntariness, and therefore the autonomous nature, of the choice in question. While there will almost certainly be circumstances in which voluntariness will be seriously compromised by manipulative or coercive influences, it may still be the case that unrestricted access to PGD is the best available means of protecting autonomy. That this is so may become clearer when consideration is given to the fact that a great many other choices of substantial importance are made in a similar environment.

In recent years, the view that decisions to procreate take place within an environment which portrays childbirth overwhelmingly as desirable, or even inevitable, has become increasingly accepted. Thus, it has been contended that 'the context in our culture is such that a childless woman is an unenviable social anomaly,'[128] and that

> [t]he ideology of obligatory fertility and the definition of women in terms of reproductive destiny and fulfilment is one of the most powerfully oppressive psychological forces bearing down on married heterosexual women of childbearing age.[129]

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[126] Chadwick and Ngwena, 'The Development of a Normative Standard …', loc. cit.,at p.277.
[127] Clarke, Introduction to *Genetic Counselling: Practice and Principles*, op. cit., p.19.
[128] Paul Lauritzen, 'What Price Parenthood?', from *Life Choices: A Hastings Center Introduction to Bioethics*, eds. Joseph H. Howell and William Frederick Sale, Georgetown University Press: Washington D.C., 1995.
[129] Kathryn Pauly Morgan, 'Of Woman Born?...', from *The Future of Human Reproduction*, op. cit., at p.70.

Indeed, the perspective of contemporary society which views it as overwhelmingly pro-natalist is becoming so widely held in some disciplines that it may even be considered the orthodox view. Does this lead inevitably to the view that *all* reproductive decisions are subject to such influence as to invalidate any purported exercise of autonomy?

In many areas of life, decisions are made in the context of a society which makes its endorsement of one set of choices rather than another quite explicit. The choice of one's sexual partner, for example, takes place within the context of a society which may be seen only fully to approve of monogamous heterosexual relationships between persons of the same race and religion.[130] Decisions concerning modes of dress, for example, and products purchased may lack the dimension of moral disapproval which accompany the other decisions mentioned so far, but there is a very real case for supposing that the influence exerted by both advertising and peer pressure is substantial.

Perhaps Katz Rothman is correct when she suggests that 'what we should realise is that human beings living in society have precious little choice ever. There may really be no such thing as individual choice in a social structure,' she proposes, 'not in any absolute way. ... Society, in its ultimate meaning, may be nothing more and nothing less than the structuring of choices.'[131] This view is closely related to that of *dialectic determinism*, the perspective which holds that 'people never act entirely voluntarily, that is, independently of societal conditions, nor entirely involuntarily, that is, totally dependently on these conditions.'[132] If this assessment is accurate, then it is not just decisions about PGD and prenatal screening which 'lead[ ] to doubts that assumptions of "free choice" ... are appropriate.'[133] Many of the most intimate and important decisions in life are, on this view, not true exercises in voluntariness at all, but responses elicited at least in part by the weight of societal pressure.

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[130] In many respects, it could be argued that the influence imposed by society to restrict one's sexual activities to partners of the opposite sex comes closer to Beauchamp and Childress's concept of 'coercion,' in view of the differing status of heterosexual and homosexual acts in the eyes of the criminal law.
[131] Katz Rothman, *The Tentative Pregnancy*, op. cit., p.14.
[132] Theresia Degener, 'Female self-determination between feminist claims and "voluntary" eugenics, between "rights" and ethics', *Issues in Reproductive and Genetic Engineering*, (1990); 3(2): 87-99. at p.93.
[133] Lippman, 'Prenatal genetic testing and screening: constructing needs and reinforcing inequalities', loc. cit., at p.152.

The question as to the extent of 'real choice' or 'voluntariness' which survives this immersion in influences is moot. What seems almost universally recognised, however, is that *some* measure of control over these decisions is retained by those making them. Almost no-one would contend that decisions about reproduction or choices of sexual partners are so devoid of voluntariness that we would not be worse off were these decisions overtly and completely taken over by some other party. It does not require any fanciful leap of imagination to anticipate that any attempt by the state to regulate the reproductive options of its citizens would meet with furious resistance.[134] While this recognition that things 'could be worse' does not constitute a resounding endorsement of the status quo, it does tend to suggest that there still exists something worth striving to protect, that some element of genuine choice remains. Similarly, in relation to PGD, an outcry could be foreseen if geneticists were allowed to subject all in vitro embryos to whatever tests *they* deemed appropriate. Again, this seems to involve a recognition that the present situation, while imperfect, allows the prospective mother *some* degree of control.

It may be argued, then, that while some degree of influence from counsellors, and from outside sources, is likely, or even inevitable, it is less clear that such influence is greater than the influence brought to bear on many other important and intimate choices, involving choice of sexual partner or decisions whether to have children at all. Furthermore, doubts exist as to whether the influences are sufficiently controlling to rebut the presumption that a laissez faire approach furthers the interest in reproductive choice; it is surely possible to recognise that '[w]e typically make choices in a context of competing influences, such as personal desires, familial constraints, legal obligations, and institutional pressures' but to recognise also that '[a]lthough significant, these influences need not be controlling to a substantial degree.'[135]

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[134] As evidenced on a yearly basis by student reactions to Hugh Lafolette's suggestion that prospective parents should be vetted by the state support this contention; 'Licensing Parents' (1980); 9(2) *Philosophy and Public Affairs*, 182.

[135] Beauchamp and Childress, *Principles of Biomedical Ethics*, 1994 edition, op. cit., at p.165.

However, even if there were shown to be some merit in the assertion that women would in some sense have been more 'free,' would have had more 'real choice' - or at least an 'easier' life[136] - had PGD and other screening technologies never been invented, it must be recognised that turning back the clock to 'uninvent' these technologies is not possible. The existence of PGD is now a technological *fait accompli*, and the hard questions it throws up are now a fact of life for many people. The choices on offer may be less than perfect, and are undoubtedly subject to certain pressures and influences. And for some women, a fatalistic acceptance of the cards dealt to them by the genetic lottery may have been preferable to the soul-searching required by the new technology.[137] Given that the technology does now exist, however, it may be seen that the only real issue relates to who precisely should be empowered to make the hard moral choices which accompany it. The central tenet of the Genetic Supermarket proclaims that these choices must be made by the women who will bear the children whose very existence is in question. However impure or compromised the purported exercises in choice may be in the scenarios looked at here, it is difficult to see how allowing such choices to be taken over by the medical profession or by some executive body would be preferable.

Whether, in retrospect, the changes brought about by PGD should be welcomed or regretted, whether the choices to which it has given rise have improved or diminished the lives of those women touched by this technology, it is difficult to see how denying those choices to, or taking them from, individual women can really be said to enhance their control over their own lives. As Mary Anne Warren has written with particular reference to sex selection:

> it is neither necessary nor desirable to defend women's right not to be forced to use new methods of sex selection at the expense of their right to voluntarily choose to do so.[138]

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[136] Abby Lippman has argued that 'The very availability of those technologies necessarily forces every woman at least to consider if she desires genetic testing - or if she even desires that testing be available for use by other women - and merely facing this choice is itself difficult, and often painful.' 'The Genetic Construction of Prenatal Testing: Choice, Consent, or Conformity for Women?' from *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*, ed. Rothenberg and Thomson; Ohio State University Press, 1994, at p.11.

[137] Fern, one of the women interviewed by Katz Rothman, expressed the following sentiment: "There are times when I really curse modern technology. No one should have to make these kinds of decisions.' Katz Rothman, *The Tentative Pregnancy*, op. cit., at p.182. This kind of reaction led Katz Rothman herself to speculate whether 'Maybe there are limits to the value of knowing.' Ibid, at p200.

[138] Warren, *Gendercide*, op. cit., at p197.

2.4 Justice

I have argued, then, that the question which lies at the heart of this thesis is one that should be of interest from a number of ethical perspectives other than the obvious Millian liberal utilitarianism; anyone concerned with how the liberty of the individual should be balanced against the welfare or protection from harm of others should regard this approach as worthwhile.

However, several further issues merit consideration before moving onto the specific questions which arise from the Genetic Supermarket. First, it should be noted that thus far the discussion has been confined to the question of whether and to what extent the state should *permit* access to PGD. This is, of course, a separate question from that which asks whether and to what extent the state should *provide* access to the technology in question.

As numerous writers have explained, liberty - defined as freedom from controlling influences from others - is but one component of 'autonomy'; while liberty and capacity may be all that is necessary for an autonomous *choice*, *acting* to further one's interests will often require the wherewithal - economic or whatever - to put those decisions into practice. Thus, Isaiah Berlin noted that '[i]t is important to discriminate between liberty and the conditions of its exercise. If a man is too poor or too ignorant or too feeble to make use of his legal rights, the liberty that these rights confer upon him is nothing to him ...'[139] Shelly Kagan, meanwhile, has questioned the use of the term 'freedom' as being synonymous with liberty; 'the argument from liberty,' she maintains,

> unjustifiably restricts itself to one kind of freedom - freedom from interference. ... Yet such "negative freedom," as it is sometimes called, is not the only kind of freedom with legitimate moral significance. An adequate moral system should also express the value of "positive freedom," or the ability to accomplish one's various goals.[140]

[139] Isaiah Berlin, *Introduction to Four Essays on Liberty*, New York, Oxford University Press, 1969, p.liii.
[140] Shelly Kagan, 'The argument from liberty', from *In Harm's Way*, ed. Coleman and Buchanan; Cambridge University Press, 1994, at p.17.

Whether liberty is considered valuable as an indispensable component of autonomy (as by Beauchamp and Childress), or as an instrument to the promotion of interests (as by contemporary utilitarians such as Peter Singer), it can be seen that it will rarely be considered to be the only kind of freedom that is important. If we are to be concerned about the ability of prospective parents to give effect to their wishes, and/or to choose their own life path, then perhaps it will require more than a 'hands-off' approach by the state. What, it might be asked, of those who cannot *afford* to shop in the Genetic Supermarket of Nozick's dreams?

In a sense, that is not especially relevant to the question considered here, which is essentially about whether constraints on liberty, in the form of legislative or quasi-legislative restraints, can justifiably be imposed on those who wish to use PGD. The extent to which the state should assist those who wish to use this technology is a fascinating question, perhaps as important as the question of whether it should permit them to do so. It is tempting, though, merely to note that it is not the question that is being addressed here.

There is, however, a sense in which confronting that question is unavoidable within this analysis. For one species of harm that has been suggested might flow from the Genetic Supermarket is a potential exacerbation of divisions that already afflict our society, divisions along social, economic and health lines. Allowing only those with sufficient economic means to access the Genetic Supermarket could further allow the wealthier elements of our population to ensure that their offspring are healthier, longer lived, perhaps even more intelligent or conventionally attractive than those further down the Socio-Economic scale.

While some observers have viewed this threat as a reason for curtailing access to the Genetic Supermarket (q.v. George Monbiot[141]), an alternative suggestion would be to ensure universal access to this technology. If a potential harm can be avoided while enhancing rather than curtailing liberty, then the Harm Principle would require that it is this alternative that should be followed. As Chapter 4 will suggest, however, an

[141] George Monbiot, 'Rock-a-bye baby with the perfect genes', *The Guardian*, 18 February 1997.

approach that sees the state provide universal access to PGD might bring its own problems, problems that include but also extend beyond questions of limited resources.

2.5 Impersonal or person-regarding approaches

The ethical axiom by reference to which PGD will be evaluated, then, has at its core a weighing up of the possible harm to which a laissez faire approach to this technology could give rise. Harm, as conceived by both descendants from traditional utilitarianism and by pluralists such as Beauchamp and Childress, is defined as the thwarting, frustrating, or setting back of the interests of those affected by an action or decision. But is it possible that 'harm' could take a different form, a form that does not necessarily relate to the interests of particular individual people (or perhaps also those people who inevitably will exist), but rather concerns itself with increasing the satisfied wants or interests *in the world*? The distinction between 'person-regarding' and 'impersonal' approaches is highly significant for the subject matter of this discussion, and it will therefore be considered in more depth.

An impersonal approach to utilitarian ethics would be concerned with 'the promotion of total or average happiness in the world.'[142] Rephrased in terms more suited to the axiom of interests, the objective may be seen as either the maximisation (taking account of both number and intensity) of total satisfied interests in the world - *total* utilitarianism - or the maximisation of the average level of happiness (defined, presumably, as the balance of satisfied over frustrated interests) - *average* utilitarianism.

Possible objections to the average approach are fairly obvious. The objective of the average utilitarian is to maximise the average level of 'happiness', yet this could be accomplished in one of two ways. He could certainly set about making existing individuals 'happier,' by helping them satisfy their desires and fulfil their interests. Equally, however, he could set about increasing the average level of 'happiness' by

[142] David Heyd, *Genethics: moral issues in the creation of people*, Berkeley, University of California Press, 1992, at p.120.

killing those who were less happy than average, even if those individuals have lives which are still subjectively worth living or which could easily be improved. His duty, after all, would be an impersonal one, and if this course of action would increase the average level of 'happiness' then he would surely be acting in furtherance of it.

For the vast majority of those who confront this conclusion, average utilitarianism is deemed unacceptable. It will not, therefore, be adopted as the ethical basis of this thesis. Attention will instead be turned to the other variety of impersonal approach, known as total utilitarianism. As the name would imply, this imposes a 'duty to promote the overall good in the world.'[143] This has the apparent advantage over average utilitarianism that it would not ordinarily be acceptable to kill an individual whose life was subjectively worth living - while this may increase the average level of 'happiness,' the aggregate would be decreased.

However, according to a recent article by Michael Tooley, circumstances may exist in which it would be acceptable, and perhaps even obligatory, for the total utilitarian to do exactly this. He imagines the following hypothetical case:

> suppose, for example, that one has a happy and healthy child, and that one would very much like to have another happy child, but that, unfortunately, as things stand, one is unable to raise a second child. ... [Total utilitarianism] appears to imply that, other things being equal, the best thing to do would be to kill the one child in order to have another, assuming that the life spans of the first and second child together will be longer than what the first child would enjoy if it were not killed.[144]

What is perceived by many to be the fatal flaw in the total utilitarian approach lies in the fact that the total aggregate 'happiness' could be increased by the creation of ever greater numbers of marginally happy persons. This may be so even if this was at the expense of the quality of each of these lives, since '[t]he loss in quality of life might be outweighed by a sufficient gain in the number of lives lived.'[145] This is what Parfit has referred to as *The Repugnant Conclusion*, the conclusion that

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[143] Ibid, at p.57.
[144] Michael Tooley, 'Value, Obligation and the Asymmetry Question', *Bioethics* 1998, 12(2), at p.115.
[145] Derek Parfit, *Reasons and Persons*. Oxford, Clarendon Press, 1984, at p.386.

> [f]or any possible population of at least ten billion people, all with a very high quality of life, there must be some much larger imaginable population whose existence, if other things are equal, would be better, even though its members have lives that are barely worth living.[146]

Thus, it would be required by this variant on the utilitarian axiom that all existing persons should act in such a way as to overpopulate the planet, up to that point at which the lives of the extra persons cease to increase the aggregate amount of satisfied interests. In addition, this approach could conceivably be taken to justify the exerting of pressure upon existing persons who wish to remain childless, or to procreate at less than optimum capacity; although it would frustrate certain of the interests of the reluctant parents to be coerced into producing unwanted children, this would arguably be more than compensated for by the creation of whole new worthwhile lives, even if these lives were of a fairly poor quality.

An axiom which led inescapably to the conclusion that everyone capable of bearing children should be coerced into so doing, or that existing children should be killed to make room for other children with more worthwhile years ahead of them, would be very unlikely to meet with widespread acceptance, and the same may presumably be said of one which created a moral imperative to overpopulate the planet to the extent envisioned in the Repugnant Conclusion. It would therefore appear that either form of impersonal utilitarianism seems likely to lead very quickly to conclusions which the majority would deem repugnant, since each would involve sacrificing 'the utility of individuals to the promotion of the impersonal value of the overall good ... in the world.'[147]

The alternative would be to adopt a *person-regarding approach*, that is to say, an approach which holds 'that value is analytically related to the needs and wants, interests and ideals of actual human beings and cannot be ascribed "to the world."'[148] Such an approach may be intuitively more appealing, in that it would not require us to regard the wants of existing persons as being secondary to some abstract,

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[146] Ibid, at p.388.
[147] Heyd, *Genethics*, op. cit., at p.57.
[148] Ibid, Preface.

impersonal ideal.[149] It is therefore a person-regarding approach which will be adopted for the remainder of this thesis.[150] However, as will become clear in subsequent chapters, the person-regarding approach requires further clarification, particularly when considering which persons have interests worthy of consideration. Furthermore, it is an approach which yields its own share of results which many will regard as intuitively unappealing.

2.6 Means, ends and harms

In its report on PGD for tissue typing, discussed earlier in this chapter, the HFEA Ethics Committee addressed the 'putative child's actual moral, psychological, social and physical welfare'.[151] In so doing, it considered both a fairly traditional formulation of the 'welfare principle', asking 'whether the outcome of the technique adversely shifts the balance of benefit and harm',[152] together with a more unusual formulation where the Committee considered the proposition that:

> It could be suggested that positive consideration of the welfare of the child requires respect for beings as ends and that the putative child be treated not merely as a means to a further end but also as an "end in itself".[153]

This concern derives – as the Committee acknowledged – from Immanuel Kant's categorical imperative that each person must be treated as an end in him or her self, and never merely as a means.[154] As a distinct species of ethical principle, the imperative is widely acknowledged and respected, but it would seem that, in this case, the Ethics Committee regarded it within the context of the welfare principle. If being treated merely as a means rather than an end in itself would have adversely

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[149] It may also be expected to be less intuitively repellent to those who subscribe to the Kantian imperative that no person should be treated solely as a means to some other end.

[150] Once again, it is not being contended that either of the impersonal approaches would constitute an axiom which is internally logically incoherent. Rather, the total and average approaches are being rejected on the grounds that they lead to conclusions which would result in their being deemed unacceptable by almost everyone. It is further contended that an examination of PGD, or any other topic, from an ethical perspective to which no-one adheres would be of negligible interest to prospective readers and negligible practical value to the debate.

[151] Ethics Committee of the Human Fertilisation and Embryology Authority, *Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors*, 22 November 2001, at paragraph 3.2

[152] Ibid, at paragraph 2.14

[153] Ibid, at paragraph 2.9

[154] Immanuel Kant, *Groundwork of the Metaphysics of Morals*, 1785, Cambridge, Cambridge University Press, 1998.

affected the future child's welfare, then it may be that such treatment is being considered as a species of harm, albeit of a less tangible variety.

It is by no means clear that the Kantian imperative should be regarded as being concerned with harm, rather than as a proposing a distinct and separate ethical concern. Certainly, on some conceptions, the categorical imperative seems to be concerned more with motives and mindsets than with interests and harms.[155] By the same token, however, it is not unintelligible to attribute to any future child an interest (whether or not they are aware of it) in being treated as an end in themselves, and if such an interest is deemed to exist, then its frustration might well be regarded as a harm.

Given this ambiguity, and given that the HFEA and its Ethics Committee placed considerable emphasis on this imperative when considering the 'welfare' of the future child, the possible harm inflicted when a child (or a potential future child, as the case may be) is treated only as a means will be considered further in Chapter 5.

2.7 A rejection of rights?

The second apparent omission from the perspective to be adopted here relates to the concept of rights. The failure to accommodate a rights-based perspective within this thesis might seem like a substantial oversight. From the mid-Twentieth Century onwards, the language of rights has occupied a central place in jurisprudential discourse.[156] While the immediate aftermath of the Second World War and particularly the Holocaust saw nations rush to endorse the notion of human rights in fairly abstract form,[157] the decades that followed saw legal theorists dedicate themselves to the details: defining what rights meant, discussing from whence they

[155] See, for example, the attitude of the HFEA Ethics Committee towards tissue typing for the benefit of a parent, considered further in Chapter 5.

[156] Brenda Almond reminds us that the concept of rights can be traced back at least as far as Grotius and Locke in the Seventeenth Century, but that the Nineteenth and early Twentieth Centuries saw 'appeal to rights ... eclipsed by movements such as utilitarianism and Marxism which could not, or would not, accommodate them.' 'Rights', in Singer, P., ed. *A Companion to Ethics*, op cit, at p.259.

[157] q.v. United Nations Declaration of Human Rights 1948, European Convention for the Protection of Human Rights and Fundamental Freedoms 1950.

derived their ethical force, listing and ranking rights and constructing a mechanism for adjudicating between them when they compete.[158]

As the discourse on rights became more refined, it began to specialise and subdivide, such that specialist literatures emerged dealing with particular rights. The 1970s and 1980s saw one such body of literature emerge that is of particular relevance for the subject of this thesis: the right to reproduce. As Sheila McLean has noted, the notion of a right to reproduce has two facets: the negative states that 'no person or organization has a right to interfere with an individual's existing capacity to procreate', while the positive facet 'may even imply that there is some duty, for example, on states, to facilitate reproduction.'[159]

It is immediately clear that at least the former of these manifestations of a right to reproduce could have important implications for the idea of the Genetic Supermarket, for while it is not entirely obvious that a negative right to reproduce implies a right to choose the genetic characteristics of one's offspring, it is at least an arguable derivation from that right. Why, then, is a rights-based analysis being neglected here?

It is my contention that an examination of the Genetic Supermarket hypothesis from the perspective of a right to reproduce, while interesting, may in fact be superfluous. This conclusion, I submit, follows from a consideration of the conventional understanding of a right as being a species of interest that is afforded special weight, over and above what is afforded to other interests. In his seminal *Taking Rights Seriously*, Ronald Dworkin speaks of rights in the following terms:

> Of course, a responsible government must be ready to justify anything it does, particularly when it limits the liberty of its citizens. But normally it is sufficient justification, even for an act that limits liberty, that the act is calculated to increase what

[158] For a variety of perspectives on these and other questions, see, inter alia, Dworkin,. *Taking Rights Seriously*, op cit; Nozick, *Anarchy, State and Utopia*, op cit; Alan Gewirth, *Human Rights: Essays on Justification and Applications*, Chicago, University of Chicago Press, 1983; John Finnis, *Natural Law and Natural Rights*, Oxford, Clarendon Press, 1980.

[159] Sheila McLean, 'The Right to Reproduce', in Tom Campbell, ed. *Human rights: from rhetoric to reality*, Oxford, Blackwell, 1986, at p.99. It should be noted that it is by no means unanimously agreed that the 'right to reproduce' is a distinct species of right, as opposed to one aspect of a right to bodily integrity, or indeed liberty.

> the philosophers call general utility – that it is calculated to produce more over-all benefit than harm. ... When individual citizens are said to have rights against the Government, however, like the right of free speech, that must mean that this sort of justification is not enough. ... Someone who claims that citizens have a right against the Government need not go so far as to say that the State is *never* justified in overriding that right. ... What he cannot do is say that the Government is justified in overriding a right on the minimal grounds that would be sufficient if no such right existed. He cannot say that the Government is entitled to act on no more than a judgment that its act is likely to produce, overall, a benefit to the community.[160]

What Dworkin is saying, then, is that while justification is needed for overriding *any* interest, those designated as *rights* are elevated to a higher plane whereon a more onerous burden of justification applies. Thus, rights as conceived of by Dworkin have come to be described as 'trumps', automatically assumed to outweigh other interests and lifted above the usual balancing of harms and benefits.

If such a 'trump' status is to be applied to reproductive liberty, and if that liberty is thought to encompass the freedom to make use of the Genetic Supermarket, then clearly prospective consumers would have a stronger case than if they are deemed merely to have an interest in being allowed to make such choices. But if the mere fact of having such an interest is itself enough to safeguard the such an exercise of liberty, if a case can be made out from the general liberty principle, then having recourse to a particular 'trump' relating specifically to reproductive freedom might ultimately prove unnecessary. If a mere *interest* in being allowed to choose the genetic makeup of one's future offspring is shown to outweigh the suggested harms that this would cause, then there is no need to 'supercharge' that interest by designating it a *right*.

2.8 Conclusion

In this chapter, I have sought to demonstrate that the language of harm continues to occupy a prominent role within bioethical discourse. Legislators and regulatory bodies continue to phrase their questions and conclusions in terms of harm, potential

[160] Ronald Dworkin, *Taking Rights Seriously*, London, Duckworth, 1977, at p.191.

or actual, while bioethics commentators on both liberal and conservative sides of debates concern themselves with it. For adherents to the Harm Principle such as Charlesworth, harm is an indispensable precondition for legal intervention in matters of individual liberty, while for ethical pluralists it is but one concern among several, but almost no-one would seek to argue that it is of no significance at all.

I have then attempted to elucidate what we might mean by harm, adopting the view popularised by Feinberg that it involves the thwarting, setting back or frustrating of an interest. I have referred to, but not yet explored in depth, the possibilities that being treated as a means to an end, or treated unjustly, may constitute 'metaphysical' harms regardless of any tangible adverse effect on the individuals concerned, possibilities to which I will return in later chapters.

Chapter 3 The Children of the Genetic Supermarket

The question at the heart of this thesis, then, is whether any harm can be said to result from unfettered access to the Genetic Supermarket. If this question is answered in the affirmative, then a second category of questions arises, concerning the magnitude of that harm and the cost, in terms of other harms, of avoiding it. For it may well transpire that there is no way to respond to the possibilities offered by PGD that does not involve the infliction of some harm on someone.

The immediate task, however, is to consider whether any harms would arise from the default position. As explained in the previous chapter, the Harm Principle traditionally takes as its default position the presumption that the law should not interfere with people's choices. Only if it can be demonstrated that the laissez faire position gives rise to greater harms than those inherent in legal restriction can that presumption be said to be rebutted, and curtailment of liberty justified. What, then, are the harms thought to arise from the unregulated Genetic Supermarket? Or, to phrase the question in another way, whose interests are likely to be affected by the choices allowed by PGD?

3.1 Harm to the deselected embryos

An obvious group of candidates for classification as 'interested parties' are the embryos themselves. As explained in the opening chapter, the decisions made in the wake of the *in vitro* fertilisation of several ova will be concerned with which of several cryopreserved embryos will be implanted in the uterus, and which will not. The respective fates awaiting the two groups could not be more dissimilar. For those which are selected, the possibility[1] that they will one day be born into an environment where they are much wanted beckons, while for the 'unsuccessful' candidates, the future holds only the prospect of destruction, perhaps after being the subjects of experimentation. In view of this situation, the conclusion that the embryos have some interest in what is decided might seem an obvious one.

[1] It must of course be remembered that this *is* only a possibility; the majority of embryos implanted after IVF will not result in a successful pregnancy. See *The Patients' Guide to DI and IVF Clinics*, 3rd Edition (1997), published by the Human Fertilisation & Embryology Authority.

However, for a number of reasons, the determination as to whether the embryos qualify as interested parties is considerably more problematic. Certainly, any decision will have an *effect* upon the embryos; but this is not the same as saying that the embryos have interests which will be affected thereby. Any attempt to make a determination as to whether the interests of the cryopreserved embryos should enter into an evaluation of the potential harm caused by PGD will of course depend upon the answer to the question as to whether embryos are the kinds of beings which are capable of having interests at all.

This part of the 'embryo question' can be answered with some brevity. In the previous chapter, I submitted that the sort of interests the frustration of which give rise to harms are those which relate, albeit not always directly, to wants. There, I argued that while it is not unknown to hear people ask whether a particular weedkiller might harm his lawn, this was not harm in the normative sense; we do not feel any sympathy for, nor empathy with, the lawn, do not feel that it has sustained any loss that is meaningful to *it*.

The question as to whether a being is the bearer of that type of interests with which we are concerned, then, depends upon the possession of wants, which in turn rely on the possession of *consciousness*. That is to say, for interests to be meaningfully attributed to any person, that person must be, or at some point have been,[2] conscious. Thus, it has been observed that

> it is both a necessary and sufficient condition for having interests, in the sense that is relevant to the question of moral status, that one be conscious in the minimal sense of that term,[3]

and that

> [i]t makes no sense to suppose that something has interest of *its own* - as distinct from its being important what happens to it - unless it has, or has had, some form of consciousness: some mental as well as physical life.[4]

The question of when precisely a human being attains a level of consciousness sufficient for us to attribute to it even the most basic of interests[5] has still not been answered to the satisfaction of all, but although this is of great importance in any consideration of the

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[2] The question of whether interests can survive the being who harboured those interests is philosophically contentious, and will be considered again later in this chapter.

[3] J.A. Burgess and S.A. Tawia. 'When Did You First Begin To Feel It? - Locating The Beginning Of Human Consciousness' *Bioethics* (1996) 10(1);1 at p25

[4] Ronald Dworkin, *Life's Dominion* at p.

[5] It is usually assumed that an interest in avoiding physical pain accompanies the onset of sentience (the ability to experience that pain), and predates any other experiential interest. See, e.g. Dworkin, *op cit*.

ethics of abortion, for example, it may be seen that ascertaining the precise timing of the onset of consciousness is not necessary for the present discussion. For while doubt may exist as to when consciousness is first present in a human being, no-one would seriously seek to attribute that quality to an eight-cell embryo.

The reason for this certainty lies in recognition of the fact that, in order for consciousness to be possible, a being must fulfil certain physiological criteria.[6] As Burgess and Tawia have commented,

> (mental) facts about human consciousness are supervenient on (physical) facts about the human central nervous system - more specifically, they are (at least largely) supervenient on facts about the cerebral cortex,[7]

that is, 'the folded sheet of gray matter ... that covers the surface of the cerebral hemispheres'.[8]

When precisely an adequate neural substrate for sentience can be assumed to be present is the subject of some dispute. A review of the literature does suggest, however, that there is no serious doubt that the possibility of sentience does not exist until a relatively advanced stage of the pregnancy. Thus it has been claimed that

> it appears unlikely that the neural apparatus with which the foetus is endowed is capable of much more than unconscious reflex activity until at least midgestation and perhaps much later.[9]

The Royal College of Obstetricians and Gynaecologists Working Party were somewhat more specific, observing that 'thalamocortical connections are first observed penetrating the frontal cortical plate at 26-34 weeks' gestation' and stating that 'before that time there is no sensory input to the cortex.'[10]

Indeed, so widely shared is this view among embryologists and neurologists that to describe it as the orthodox view is something of an understatement - as Bonnie Steinbock has said,

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[6] 'an interest, however the concept is finally to be analyzed, presupposes at least rudimentary cognitive equipment. Interests are compounded out of *desires* and *aims*, both of which presuppose something like ... cognitive awareness.' Joel Feinberg, 'The Rights of Animals and Unborn Generations', from *Rights, Justice, and the Bounds of Liberty, op. cit.*, p.168.

[7] Burgess and Tawia, 'When Did You First Begin To Feel It?', loc. cit., at p.2.

[8] Rodrigo O. Kuljis. 'Development of the Human Brain: The Emergence of the Neural Substrate for Pain Perception and Conscious Experience', from *The Beginning of Human Life*, Beller and Weir, eds., Dodrecht, Kluwer Academic Publishers, 1994, at p.50.

[9] Ibid, at p.55.

[10] RCOG Report, at p.16. See also Grobstein, *op cit*, at p.55.

> there is complete agreement that the very early embryo cannot be sentient, because it has not yet developed the rudimentary structures of a nervous system.[11]

Even Elizabeth Peacock of the UK Parliamentary Pro-Life Group does not allege that the capacity for pain exists prior to ten weeks.[12] Thus, embryos do not and can not in any sense be said to care about what happens to them, or indeed care about anything at all; '[w]hether they are preserved or destroyed, cherished or neglected is of no concern to them.'[13] This does not of necessity lead to the view that what happens to an embryo is a matter of moral indifference; other individuals may have interests bound up with the fate of the embryos, and other ethical principles may be violated if they are treated in certain ways.[14] Nonetheless, it is as well to be clear at this point that, if it is possible to treat an embryo in ways that may be said to be 'wrong,' it is not because the embryo itself is being harmed in any subjectively meaningful sense; 'a being without interests has no "behalf" to act in, and no "sake" to act for.'[15] In short, it cannot be harmed.

What could be argued, however, is that they possess the *potential* to become beings with interests. Establishing that there exists no reason to be concerned about the interests of the embryos - quite simply, they have none - does not address the question of whether concern ought to be due to the future interests of the persons[16] those embryos have the potential to become. For many adherents to the view that embryos are of moral significance, it is this potential which renders those lives valuable. There are, however, persuasive reasons to reject that argument. As Harris has pointed out,

> the fact that an entity can undergo changes that will make it significantly different does not constitute a reason for treating it as if it had already undergone those changes,[17]

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[11] Bonnie Steinbock, 'The Moral Status of Extracorporeal Embryos', from *Ethics and Biotechnology*, eds. Dyson and Harris, Routledge, 1994, at p.84.
[12] *The Guardian*, 22 July 1996.
[13] Steinbock, 'The Moral Status of Extracorporeal Embryos', loc. cit., at p.81.
[14] Steinbock draws an illuminating parallel with the issue of flag burning in the USA.
[15] Joel Feinberg, 'The Rights of Animals and Unborn Generations', from *Rights, Justice, and the Bounds of Liberty, op. cit.*, at p167. A rare opposition to this view can be found in Francis Fukuyama's *Our Posthuman Future: Consequences of the Biotechnology Revolution*, New York, Faber, Strauss and Giroux, 2002. Fukuyama claims 'that embryos are routinely harmed by in vitro fertilization clinics when they are discarded' (p.91), but makes no attempt to situate this assertion within the context of the debate as to whether embryos are the sort of beings than can be harmed.
[16] For the purposes of this thesis, the term 'person' may be taken to denote any being to which interests can meaningfully be attributed. In so saying, it is acknowledged that many writers in this field have set the threshhold for personhood considerably higher. For example, in *Wonderwoman and Superman*, John Harris defines a person as 'a creature capable of valuing its own existence' (p.68).
[17] Harris, *Wonderwoman and Superman*, op. cit., at p.34.

adding somewhat flippantly that '[w]e are all potentially dead, but no one supposes that this fact constitutes a reason for treating us as if we were already dead.'[18]

Furthermore, many ethicists have drawn attention to the fact that, were a duty 'to protect and actualize all human potential'[19] held to exist, it would logically extend beyond a duty to refrain from killing embryos. As Harris has stated,

> it is not only the fertilised egg, the embryo, that is potentially a fully-fledged adult. The egg and the sperm taken together but as yet un-united have the same potential as the fertilized egg. For something (or somethings) has the potential to become a fertilised egg, and whatever has the potential to become an embryo has whatever potential the embryo has.[20]

Following the same logic, Singer has noted that the potentiality argument 'does not provide any means for thinking abortion worse than any other means of population control,'[21] including

> contraception, whether by "artificial" means or by "natural" means such as abstinence on days when the woman is likely to be fertile; and also celibacy.[22]

It may also be seen that the argument from potentiality has even less merit when applied to extracorporeal embryos. Steinbock has pointed out that the potentiality argument depends upon the view that

> fertilization marks the beginning of an ongoing process which, if it is not deliberately interrupted, has a pretty good chance of resulting in the birth of a baby.[23]

This may form a good description of the ordinary pregnancy, but it can in no way be seen as applicable to IVF. As Steinbock has noted, there is no possibility of the *ex utero* embryo developing into anything else '[u]nless someone intervenes, and transfers the embryo into a uterus.'[24]

It should, perhaps, be noted that the foregoing applies specifically to *experiential* interests, i.e., those interests that relate to the subjective experiences of the being in question. In recent years, a trend has emerged in bioethics towards respect for another

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[18] Id.
[19] Id.
[20] Id.
[21] Peter Singer, *Practical Ethics*, Cambridge University Press, 1993, at p.155.
[22] Id. See also Ronald Dworkin, *Life's Dominion*, London, HarperCollinsPublishers, 1993, at p.16.
[23] Steinbock, 'The Moral Status of Extracorporeal Embryos', loc. cit.,at p.85.

form of interests, which do not rely on the present subjective mind-state of the interest-bearer. Ronald Dworkin has dubbed these *critical* interests,

> Interests that it does make their life genuinely better to satisfy, interests they would be mistaken, and genuinely worse off, if they did not recognize. Convictions about what helps to make a life good on the whole are convictions about those more important interests. They represent critical judgments rather than just experiential preferences. Most people enjoy and want close friendships because they believe that such friendships are good, that people *should* want them.[25]

If the critical interest thesis is accepted, this might lend ethical credence to the widely held belief that the wishes of the deceased, the permanently unconscious or the senile should be respected even once they cease to be aware of such wishes. Many people, it may reasonably be assumed, care deeply that their bodies are treated in a 'dignified' manner after their death, despite the realisation that, at that time, they will have neither awareness of nor concern with such matters. The notion of critical interests adds both coherence and ethical force to such feelings.

Could presentient embryos be said to possess something akin to critical interests, vesting them with an interest in, for example, not being turned into earrings?[26] A closer examination of the concept of critical interests suggests that their application to preimplantation embryos may be somewhat problematic. In each of the scenarios examined in the preceding paragraphs, the party to whom the critical interests were attributed, although now no longer aware of their existence, at one time harboured beliefs, values and preferences from which these interests can be said to derive. If the vegetative patient can be said to possess a critical interest in not being used as a sideboard,[27] this, we might think, is because he once harboured values that would be offended by such treatment of his corpse. And if the deceased person has a critical interest in being remembered in a particular fashion, this is because, when alive, she wished to remembered in that fashion.

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[24] Id.

[25] Ronald Dworkin, *Life's Dominion*, op. cit., at pp.201-202. In his more recent work, Dworkin has rephrased this distinction in terms of critical and volitional well-being; *Sovereign Virtue: The Theory and Practice of Equality*, Cambridge, London, Harvard University Press, 2000, at p.242.

[26] Matti Häyry and Heta Häyry, 'The bizarre case of the human earrings'. *Philosophy Today* 7, 1991, 1-3. Reprinted in: *Bioethics News* no. 4, 1991, 23-24.

[27] To borrow John Keown's *reductio ad absurdum*; 'Restoring Moral and Intellectual Shape to the Law After *Bland*', *The Law Quarterly Review* (1997); 113: 481-503, at p.494.

The attribution of continuing interests to those who are no longer aware of them is problematic in itself, especially when we come to consider whether any harm would result if those interests were frustrated (who, it might be asked, would sustain the harm?), and turn to the vexed question of how such interests should be weighed against the contemporaneous, experiential interests of the incompetent individual who now exists (see Appendix). However, for present purposes, it is sufficient to observe that the extension of critical interests to that class of beings that do not possess, and have *never possessed*, experiential interests, would involve extending the thesis onto even more treacherous ground.

While the nature of the critical interests which we may want to attribute to the deceased can be derived from the interests they harboured while alive, it is difficult to see how we might arrive at a similar body of critical interests for the embryo. Critical interests, as conceived by Dworkin, 'represent critical *judgments* rather than just experiential preferences',[28] while he goes on to add that '[m]ost people enjoy and want close friendships because they *believe* that such friendships are good'.[29] Preimplantation embryos being capable of neither forming judgments nor holding beliefs, it is at least questionable whether critical interests, at least as Dworkin describes them, could be attributed to them.

Indeed, it is difficult to see how any interests attributed to the embryo could be any more than projections of our own views and preferences, or perhaps of those that we might assume the embryo would one day possess if it survived until sentience. Whether any weight should be accorded to such presumed future interests will be the subject of the next section. For now, it is sufficient to note that, even if such interests can be attributed to the potential future person that the embryo might some day become, they cannot be attributed to the embryo itself.

3.2 Potential persons: those who might have been

The fact that the embryos have the potential to become morally valuable beings, or interest bearers, if some other party intervenes and treats them in a particular way, then, does not provide a reason to accord value to the embryos themselves. Does it, however,

[28] Dworkin, *Life's Dominion*, op. cit., at p.202, emphasis added.
[29] Id., emphasis added.

necessarily follow that no value should be accorded to the potential future persons which could have existed? In deciding not to implant a particular embryo, do we harm the potential future person who that embryo could have become? Should we be concerned about those potential lives that, as one participant in a discussion group once put it, are left to 'wither on the vine'?[30]

A recent proponent of this kind of harm is Francis Fukuyama. In his most recent book, Fukuyama addresses the perceived excesses of biotechnology. In the context of a discussion of preimplantation gender selection, he makes the following claim:

> In many Asian cultures, having a son confers clear-cut advantages to the parents in terms of social prestige and security for old age. But it clearly harms the girls who then fail to be born.[31]

The arguments surrounding the particular issues raised by gender preselection will be discussed in Chapter 5. For present purposes, what is of interest about Fukuyama's claim is the tacit assumption that a being which has never existed can be the subject of harm.

That this assumption is problematic should become clear when we consider the relationship, discussed at length in the previous chapter, between harms and interests. Following Feinberg, it was suggested that a harm occurs when an interest is thwarted or frustrated. The concept of 'interest' was somewhat complicated when consideration was given to Ronald Dworkin's controversial notion of critical interests, but not even Dworkin would dispute that interests can only meaningfully be attributed to beings which exist, or have existed.

To argue that a potential future person has an interest in being brought to existence is problematic for at least two reasons. First, this claim would seem to fly in the face of the earlier suggestion that interests are a product of awareness. Embryos, it was argued, have no interests, because they lack even a basic awareness of their surroundings, and have not even the most rudimentary preferences. If this is true of embryos, then it is surely at least as true of the ethereal class of 'potential persons', which at the time of the implantation decision, exist more as hypothetical concepts than as actual entities.

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[30] Cited in Colin Gavaghan, 'Off-the-peg Offspring', *Philosophy Now*, Winter 1998-1999

[31] Francis Fukayama, *Our Posthuman Future: Consequences of the Biotechnology Revolution*, New York, Faber, Strauss and Giroux, 2002, at p.97

A second objection to Fukuyama's attribution of harm to 'those who might have been' arises when we consider the question of numbers. How many such potential future persons are harmed? It is a straightforward matter to count the number of embryos discarded in a fertility clinic. But if we are concerned not with embryos per se, but with potential persons who might have lived but for our decisions, then we cannot confine the calculation to that setting. What of the potential persons who might have lived had the prospective parents harvested more ova and implanted more embryos?[32] And those who might have lived but for the availability of contraception? Or for lifestyle choices like celibacy, voluntary childlessness or deferring reproduction until later life? The potential future girl who might have lived in Fukuyama's hypothetical scenario has no more actual existence, and no more *right* to existence, than the potential future children who might have lived but for any of the other choices that limit the number of children brought into the world.

The sort of conceptual confusion underlying Fukuyama's contention can also be found in an argument advanced almost thirty years before by R. M. Hare. In an article entitled 'Abortion and the Golden Rule', Hare sought to develop an argument along the lines that, if an individual is now glad to be alive, then being born was clearly a benefit to him; and if this is so, then it follows that an act – such as abortion – that prevented his being born would have constituted a harm to him. 'If it would have been good for him to exist,' Hare argued, 'surely it was a harm to him not to exist.'[33]

This sort of harm-benefit symmetry is problematic in many other settings. Michael Bayles has claimed that, from the fact that an act may confer benefit on someone - giving him $500, for example – it does not follow that omitting to so act harms him. In arguing otherwise, Bayles maintains, Hare 'has collapsed the distinction between harm and nonbenefit'.[34] The Hare-Bayles dispute raises a serious question for the ethics of harm , specifically: if I have it within my power to benefit someone, and I elect not to do so, does it immediately follow that I have harmed him?

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[32] In practice, there is a limit imposed on the number of embryos that can be implanted in each cycle of IVF, a policy was framed without apparent concern for the potential future lives sacrificed by this limit.
[33] R. M. Hare, 'Abortion and the Golden Rule' *Philosophy and Public Affairs* (1975); 4(3): 208, at p.221.
[34] Michael D. Bayles, 'Harm to the Unconceived' *Philosophy and Public Affairs* (1976); 5(3): 292-304, at p.298.

This was discussed briefly in Chapter 2, but fortunately, it need not detain us further here. For whether or not Hare's claim is true with regard to gratuitous donations of money, it is almost certainly not true with regard to the present question. 'Genesis questions' have certain distinct characteristics that render Hare's claim particularly problematic. The fact that a person is relieved that his parents brought him into existence does not support the conclusion that any such interests existed when the decision about abortion was reached. In Bayles' hypothetical scenario, Smith may not harm Jones when he declines to give him the $500, but it is at least coherent to speak of Jones having interests that are affected by Smith's decision. If, however, the alleged harm that Smith had visited upon Jones took the form of a decision not to implant the embryo that would some day have become Jones, then it appears that Jones had no interests bound up in the outcome of Smith's decision at the time Smith made that decision. Furthermore, the nature of Smith's decision is such that he ensures that Jones will never acquire any interests that are affected by Smith's earlier decision.

Thus, Parfit, while sharing Hare's view that causing someone to exist may indeed confer a benefit upon him,[35] does not accept Hare's purportedly symmetrical conclusion that preventing him from existing inflicts a harm. 'Causing someone to exist,' Parfit contends,

> is a special case because the alternative would not have been worse for this person. ... When we claim that it was good for someone that he was caused to exist, we do not imply that, if he had not been caused to exist, this would have been bad for him. ... We are not claiming that it is bad for possible people if they do not become actual.[36]

Similarly, Harris asserts that

> to cause someone to exist is to benefit that person, but to cause someone not to exist by failing to bring them into existence harms no one; for the simple and sufficient reason that there is no one who suffers this misfortune.[37]

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[35] Parfit, *Reasons and Persons*, op. cit., at p489.
[36] Id.
[37] Harris, *Wonderwoman and Superman*, op. cit., at p55. See also Melinda Roberts, *Child versus Childmaker*, Maryland, Rowman and Littlefield Publishers, Inc., 1998, at p.11: 'we cannot wrong those who we refrain from ever bringing into existence.'; Joel Feinberg, *The moral limits of the criminal law. Vol.1: Harm to others.* New York, Oxford, Oxford University Press, 1984, at pp.96-97; Hans S. Reinders *The Future of the Disabled in Liberal Society: An Ethical Analysis*, Notre Dame, Indiana, University of Notre Dame Press, 2000, at p.40.

If harm is inextricably linked to interests, and non-existent people have no interests, then it is meaningless to speak in terms of causing them harm. To seek to attribute interests, in existence or anything else, to those who were never born seems to require a belief in some sort of extracorporeal waiting room, a 'a strange never-never land from which phantom beings are dragged struggling and kicking into their mother's wombs and thence into existence as persons in the real world.'[38]

3.3 Potential persons: those actually born

This conclusion does not, however, inevitably commit us to the view that potential future persons are outwith the sphere of legitimate ethical concern. According to the 'person affecting' approach discussed at the end of the last chapter, 'an action is only right or wrong where there are people who are better or worse off than they would have been on some alternative.'[39] However, this says little about which persons ought to be considered. Quite clearly, an existing person whose interests seem likely to be affected by a course of action must be considered in evaluating the ethical propriety of that action. It is equally clear that those persons who would have existed had a particular contingency come to pass, but who will now never exist, cannot be said to have interests in that action. It is submitted, however, that the weight to be attached to that class of persons, about whom it may be said that they either *will* or *might* exist as interest-bearers at some point in the future, is the subject of some doubt.

It could, perhaps, be argued that a moral axiom may be constructed in such a way as to require concern to be shown only for the interests of presently existing persons. This would, however, require some conclusions to be arrived at which, it may be assumed, few people would find satisfactory. Parfit has illustrated the duties he claims are owed to future generations with the following hypothetical example.

> Suppose that I leave broken glass in the undergrowth of a wood. A hundred years later this glass wounds a child. My act harms this child. If I had safely buried the glass, this child would have walked through the wood unharmed. Does it make a moral difference that the child whom I harm does not now exist?[40]

Anyone who would answer this rhetorical question in the negative would seem to be sharing Parfit's view that 'Remoteness in time has, in itself, no more significance than

[38] Joel Feinberg, *Harm to Others*, op. cit.. at p101
[39] Jonathan Glover, *What Sort Of People Should There Be?* London, Penguin, 1984, at p.146.
[40] Parfit, *Reasons and Persons*, op. cit., at p.356.

remoteness in space',[41] a view he shares with Glover,[42] Feinberg,[43] and many other bioethicists.[44] Thus, it would be wrong to bury radioactive material in such a way that it will be rendered safe for only two hundred years, despite the fact that no one alive today is likely to suffer as a consequence.[45]

But if it is assumed that abandoning the broken glass, or burying the radioactive waste, are harmful acts, the question inevitably arises as to where the subject of the harm is located. At the time I abandon the glass, the party who eventually sustains harm because of that act does not exist, and therefore cannot – following the logic of the preceding section – be the subject of harm. Indeed, following Parfit's example, no harm is caused by my carelessness until long after the end of my own anticipated life expectancy. Does it therefore follow that, at the time of leaving the broken glass, I have done nothing wrong?

The interests approach, it may be seen, does not lead to such a conclusion. For although my act inflicts no harm *at that time*, it sets in motion a chain of events that will eventually result in harm to an actual, existing person. That my act does not cause any harm at that time is undeniable, but this is not unique to the scenario wherein the eventual victim has not yet been born. In fact, the same could be said if the eventual victim is presently existing, but is currently playing in the meadow and has not yet entered the woods. If that child injures itself on the glass in six months, or five minutes, time, I could not claim that it was not harmed by my act. The extent of culpability that should attach to me will depend on various factors, including the foreseeability of the harm, and any contributory carelessness on the part of the child or its parents. But the fact of a temporal gap between my negligence and the eventual harm does not present a problem for the Harm Principle.

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[41] Ibid, at p.357.

[42] 'Why should a bias in favour of people living *now* be any more defensible than a space bias in favour of people living *here*?' Glover, op. cit., at p.66.

[43] 'We can tell, sometimes, that shadowy forms in the spatial distance belong to human beings, though we know not who or how many they are; and this imposes a duty on us not to throw bombs, for example, in their direction. In like manner, the vagueness of the human future does not weaken its claim on us in light of the nearly certain knowledge that it will, after all, be human.' Joel Feinberg, 'The Rights of Animals and Unborn Generations', loc. cit., at p.181.

[44] See, for example, Roberts, *Child Versus Childmaker*, op. cit., at pp. 15-18, Singer, *Practical Ethics*, op. cit., at p.268, and Harris, *Wonderwoman and Superman*, op. cit., at p.178.

[45] This famous example was postulated by Derek Parfit; see *Reasons and Persons, op. cit.*, Chapter .

Neither is there an insurmountable problem with the fact that my victim's actual identity is unknown (and unknowable) to me. As long as it can be predicted with a reasonable degree of certainty that the affected areas will be inhabited by some human or other sentient life, it would be wrong to act in a way likely to frustrate the interests which those beings are likely to possess.

What significance does this acknowledgement have for the Genetic Supermarket? This, it will be seen, is a far from straightforward matter. However, for the moment it is enough to note that it is meaningful to speak in terms of harming those who do not presently exist, if we know or have strong reason to suspect that they will exist at some time in the future. Unlike 'those who will never live', the subjects of the harm in this case will develop interests, and it makes sense to consider whether our actions now will give rise to a state of affairs wherein those interests will, in time, be thwarted or frustrated. That their identities are still unknowable does not mean that I cannot, with some accuracy, predict where their interests will lie; there is much that I cannot predict about the values and fashions of society a hundred years hence, but it is reasonable to anticipate that children will still have interests in not being cut by broken glass, and that everyone will have an interest in avoiding premature and unpleasant death from radiation poisoning. I should therefore avoid harmful acts, even though the harms they cause may not eventuate for many years. Furthermore, legislators may – in terms of the Harm Principle – be justified in intervening to prevent me from so acting.

3.3.1 Possible harms to future people

What kind of harms might we expect the Genetic Supermarket to inflict on the future people who emerge from its doors? The literature is replete with suggestions, but these appear to fall into two broad categories:

- Children of the Genetic Supermarket could suffer psychologically and emotionally as a result of unusual relations with their parents.

- Those children may be harmed by the particular traits chosen by parents.

To deal first with the former of these concerns, there are several ways in which future children might be thought to be harmed by their parents' use of PGD. This may be because they will be burdened with the unrealistic expectations of parents who believe

that the genotype they have selected will guarantee success in a particular field, or a particular kind of character. For present purposes, this can be deemed the *Parental Pressure Problem*.

Andrew Niccol's 1997 movie *Gattaca* postulates a dystopian future where the use of PGD is so widespread, and its consequences for employment so significant, that it has become effectively compulsory. (The suggestion that such a pressure can be brought to bear on prospective parents was considered in the previous chapter.) Much of the movie's attention is focussed on Vincent Freeman, one of the few remaining 'faith babies' (those whose parents entrusted their genotype to chance rather than science), whose ambition to go into space is thwarted by the genetic flaws which his parents did not eliminate. However, equally interesting, and perhaps more tragic, is the character of Jerome Eugene Morrow, a man so haunted by his failure to live up to the quality of his premier-quality genome that he several times attempts, ultimately successfully, to take his own life. Although to most people's eyes a successful athlete, Jerome never quite attained the supremacy that his parents expected – a failure powerfully (if unsubtly) symbolised by the silver medal which he places around his neck before his final act of self-immolation.

Is it plausible that parents who use PGD will see this as a guarantee that their children will grow up according to their expectations? Such an assumption would display a startling degree of ignorance about the interaction between genes and environment, and a naïve faith in genetic determinism. It might be hoped that counselling would dispel many such errors. However, the possibility that such pressures might be brought to bear on children of the Genetic Supermarket cannot readily be discounted.

Whether such problems would be unique to such children is, of course, a different question. Both literature and real life are replete with accounts of children who have been unable to conform to their parents' Willie Loman-esque expectations. Of course, there may be unique and unforeseeable burdens associated with being a 'designer baby'; the technology is still too new to be certain. Equally, though, it is foreseeable that there would be unique burdens associated with being born into a family with a history of criminality, or a history of notable achievement. It lies outwith the remit of this thesis to consider the complicated interaction between parental expectation, childhood stress, and the happiness of the adult that child grows into. However, it is submitted that while the

laissez faire approach to PGD could give rise to another form of parental pressure, there is at present no particular reason to suppose that it will be uniquely common or severe. There have always been unrealistic parental expectations, and some of these have even had genetics at their core, albeit a more unsophisticated genetics that simply assumed that talent would be passed through blood.[46] As Julian Savulescu has noted,

> parents inevitably have hopes and expectations for their children which are deflated every day. ... Some parents want their children to be great musicians. Sometimes this desire becomes overbearing, as depicted in the film *Shine*. But the answer is not to ban music schools. The solution is to help parents to be more tolerant and accepting.[47]

Even if this is an inaccurate prediction, however, there is another reason why this concern should not be fatal to the Genetic Supermarket, a reason that will be explored in the next section.

The suggestion has also been advanced that, irrespective of the particular choices that their parents made, those children might be resentful of the very fact that their parents made choices about their genetic composition.[48] In a sense, of course, this may seem illogical. Children, and the adults they become, presently have no control whatever over the genes they inherit. The fact, then, that their genotype was selected by parents rather than blindly selected by chance does not deprive them of any control over their own lives which they would otherwise have had.

It has been suggested, however, that while accepting the inevitability of the genetic lottery is one thing, the knowledge that one's parents had made such choices could be altogether more problematic:

> Even if an individual is no more locked in by the effects of a parental choice than he or she would have been by unmodified nature, most of us might feel differently about accepting the results of a natural lottery

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[46] q.v.. the tale of Beethoven's son, as recounted in *Immortal Beloved*, Columbia/Tristar Studios, 1994.

[47] Julian Savulescu, 'Sex selection: the case for', *Medical Journal of Australia* (1999); 171(7): 373-375, at p373

[48] 'Parents have significant control over the social and physical environment of the child, but no control over their own genetic influences. The question that is emerging is whether it is desirable to permit parents social, environmental, and biologic control over children. The issue is one of independence and individuality in their deepest senses. Such control may have a powerful psychological effect. ... We must be seriously concerned about the psychological implications for both children and parents of the knowledge (or fear) that we were carefully selected or even made to be the way we are. While there might be satisfaction all around for a child well made, there may also be a loss of full authorship in victory, and broader grounds for resentment in failure.' Jeffrey Botkin, 'Fetal privacy and Confidentiality', *Hastings Center Report* (1995); 25(5): 32-39, at p???

> versus the imposed values of our parents. The force of feeling locked in may well be different.[49]

Again, a degree of expertise in the complex psychology of parent-child relationships would be required to stand any realistic prospect of evaluating this claim, and even then the evaluation would be highly speculative. But it can be recognised that there may be unique problems in the knowledge that one's life has been pre-determined to a significant extent by another. For present purposes, this can be referred to (following Josh Parsons[50]) as the *Resentment Problem*.[51]

Fortunately for the Genetic Supermarket thesis, there is no need to discredit or reject either the *Parental Pressure Problem* or the *Resentment Problem* on empirical, psychological grounds. Rather, a more sweeping and less empirically contingent counter-argument can be raised against both claims.

3.3.2 Derek Parfit and the Non-Identity Problem

In his seminal work of consequentialist philosophy, *Reasons and Persons*, Derek Parfit postulated the now famous hypothetical example of The 14-Year-Old Girl. The imagined facts are as follows:

> This girl chooses to have a child. Because she is so young, she gives her child a bad start in life. Though this will have bad effects throughout the child's life, his life will, predictably, be worth living. If this girl had waited for several years, she would have had a different child, to whom she would have given a better start in life.[52]

If scepticism surrounding the ability to make such a prediction about the child's future life can be temporarily suspended, the question immediately arises as to whether the girl in this example can be said to have made the wrong decision. As Parfit has famously demonstrated, if any criticism may be levied at the girl's decision to have a child now, it cannot be due to any harm which has been done either to the child which she actually had, or to the child which she could have had several years from now.

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[49] Buchanan, Allen; Brock, Dan W.; Daniels, Norman; Wikler, Daniel. *From Chance to Choice: Genetics and Justice*. New York, Cambridge University Press, 2000, at pp.177-178

[50] Josh Parsons, 'Why the handicapped child case is hard', *Philosophical Studies*, October 15, 2002

[51] The question of the likely impact of parental genetic choices on parent-child relationships is also considered by Jeffrey Botkin, in 'Prenatal Diagnosis and the Selection of Children' *Florida State University Law Review* (2003); 30: 265-293, at p292.

[52] Parfit, *op. cit.*, at p.358.

The latter is an example of a never-existing potential future person, and, as was shown above, may be discounted from the array of potential subjects of harm. It never possessed, nor will it ever possess, any interests to be taken into account, and to speak in terms of its having an interest in being allowed to have interests seems circular and ultimately nonsensical. (Although this conclusion may give rise to certain counter-intuitive conclusions that will be discussed in the final section of this chapter).

What, though, of the child which the 14 Year Old Girl actually goes on to have? As a being that will have interests, it is meaningful, and arguably morally obligatory, to take these interests into account when we act, even though the harms we may cause will not eventuate for some months or years. To speak, then, of harming the future child is not incoherent. As Parfit demonstrated, though, greater difficulties are encountered when we ask what form these harms may take.

Parfit has argued that, even if its life did in fact transpire to be poorer due to its bad start in life, this is not sufficient to draw the conclusion that the girl's decision caused it harm. This becomes clear when we consider that the difficulties that the child will face were an inevitable and indispensable consequence of *that* child coming to exist at all. For *that* child, the option of being born to a more adult mother, or into a more secure environment, was simply not available. 'If she had waited,' Parfit explains, 'this particular child would never have existed.'[53]

The question, then, must be whether the child of the 14 Year Old Girl is likely to be born into a life so wretched that it would have been preferable for that child – from its own, subjective point of view – never to have been born. As Parfit suggests, 'We should ask, "If someone lives a life that is worth living, is it worse for this person than if he had never existed?"'[54] concluding that inevitably 'Our answer must be No'.[55] This is the famous Non-Identity Problem with which his work has become closely associated.

In so saying, it is being assumed - as it is by almost all commentators on this subject - that an embryo produced by this girl at a different time, resulting as it invariably would

[53] Ibid, at p.359.
[54] Parfit, *op. cit.*, at p.359.
[55] Id.

from the fusion of different gametes, would develop into a different person.[56] This notion has been referred to by Bernard Williams as the *Zygotic Principle*. Williams describes this as holding that

> the identity of human beings, as of other sexually reproducing creatures, lies in the union of two given gametes: if either the sperm or the ovum or both had been different, a different human being would have been formed and born.[57]

As will be discussed below (Appendix A), this assumption, and what some people would regard as its implicit genetic determinism, is not entirely unproblematic.

If for the moment we accept the Zygotic Principle, however, it seems that no harms - present or future - may be said to be caused by the girl's decision. That this conclusion has serious implications for the study of the GS becomes clear when we return to the question of the *Parental Pressure Problem* and the *Resentment Problem*. In both cases, to conclude that the children in question had, on balance, been harmed, we would need to conclude that these problems were so severe that the very fact of their existences constituted net harms.

Parfit's Non-Identity approach succeeds, then, in rebutting the claim that the children of the Genetic Supermarket themselves will be subjects of harm – at least in the sort of circumstances considered thus far. As such, it will have considerable importance for the question that lies at the heart of this thesis. Referring to the Non-Identity *Problem*, however, may be seen as somewhat question-begging. It seems implicit in this terminology that this approach is unsatisfactory, in need of resolution or refinement. (For Parfit, the contradiction between this conclusion and the intuitive sense that the 14 Year Old Girl should delay procreation is indeed unsatisfying, although he has admitted being unable to find a way around this without abandoning the Person-Affecting Principle.[58])

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[56] Parfit, interestingly, seems to require that *both* gametes be different before we can speak of a wholly different person. This is implicit in his statement that '[i]f any particular person had not been conceived within a month of the time when he was in fact conceived, he would in fact never have existed' (*Reasons and Persons*, op. cit., at p372), the implication being that both sperm and ovum must be different. This seems to beg the question as to how much genetic difference is required before we can speak of a 'different person'. Would a child conceived of the same ovum but a different sperm be sufficiently similar to constitute, in some sense, the same person as the child that would have been conceived a few hours or days earlier? Issues relating to the constitution of identity will be revisited at the end of this chapter.

[57] Bernard Williams, 'Who might I have been?', in *Human Genetic Information: Science, Law and Ethics* Ciba Foundation Symposium 149, John Wiley & Sons, Chichester, 1990, at p.169.

[58] Parfit, *op. cit.*, at p.443.

It is submitted, though, that there is nothing inherently problematic in this approach or the conclusion to which it leads, save that it is difficult to reconcile with some of our less-considered intuitions.[59] For that reason, this term will be replaced with reference to a Non-Identity *Principle* (NIP). It is conceded that the NIP might sometimes lead to conclusions that are counter-intuitive or unappealing. However, this is no more than could be said for the Harm Principle itself, or indeed any other ethical principle when applied in 'hard cases'. The Non-Identity Principle (NIP) is the direct offspring of the marriage of the Harm Principle and the Zygotic Principle; acceptance of those parent principles leaves us no option but to accept the NIP.

3.3.3 'Harmful' choices

The Non-Identity Principle, then, provides a response to both the *Parental Pressure* and *Resentment Problems*. Does it, however, allow us to refute the second category of purported harms that were mentioned above, the harms that would derive from the actual choices prospective parents made, rather than the mere fact of making those choices?

At first glance, the prospect of parents making such choices might seem unlikely; Fukuyama's view that '[w]e can further presume that parents will not seek to deliberately harm their children, but rather will try to maximise their happiness'[60] surely seems more plausible than a scenario where parents deliberately choose traits that could be deemed harmful. Difficulties arise, however, when we note the inherent ambiguities in the concepts of 'harm' and 'benefit' as invoked in this context. The reports of Sharon Duchesneau and Candy McCullough's attempts to ensure their child was deaf (although not actually relying on PGD technology to give effect to their choices) illustrates the controversies surrounding these concepts.[61]

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[59] Philip G. Peters, Jr., for example, asserts that the Non-Identity conclusion 'assaults our common sense' and 'simply do[es] not pass a moral gut test.' 'Harming Future Persons: Obligations to the Children of Reproductive Technology.' *Southern California Interdisciplinary Law Journal* (1999) 8: 375-400, at pp. 384-385.

[60] Francis Fukayama *Our Posthuman Future: Consequences of the Biotechnology Revolution*, New York, Faber, Strauss and Giroux, 2002, at p.92. See also Ronald Dworkin: `Presumably all parents, if given a choice, would wish their children to have the level of intelligence and other skills that we now regard as normal, or even that we now believe superior.` Ronald Dworkin *Sovereign Virtue: The Theory and Practice of Equality*, Cambridge, London, Harvard University Press, 2000, at p.441.

[61] M. Spriggs, 'Lesbian couple creates a child whom is deaf like them' *Journal of Medical Ethics*, Online eCurrent Controversies, 2 May 2002.

Much of the commentary on Duchesneau and McCullough's attempts have concentrated on the couple's claim that deafness, and more specifically membership of the Deaf community, is in fact properly regarded as a minority status, akin to membership of a racial minority, rather than a disability.[62] K. W. Anstey, for example, gives serious attention to the claim that the harms experienced by deaf children are at least in part socially constructed rather than inherent to the condition of deafness.[63] However, of interest for the present discussion is the assumption implicit in Anstey's analysis that the child in question will indeed be harmed by being born deaf. While prepared to concede the prospective parents' contention 'that it is not wrong to have a child when the harms they will experience are socially imposed,'[64] he at no point considers the possibility that the child is not a subject of harm at all.

Yet that is precisely the conclusion to which the Non-Identity Principle commits us. Duchesneau and McCullough have not taken an existing baby and rendered it deaf (although that in itself would be a scenario that poses interesting questions for the Non-Identity Principle; see Appendix A). Rather, they have brought into existence an individual for whom deafness is an indispensable prerequisite of existing at all. Had they not sought out the sperm of a deaf man, *this* child would never have existed at all, but rather would have been replaced by a different, hearing child (or, of course, by no child at all).

If we assume that deafness is not so limiting a condition, or one which imposes so much suffering, as to render a life intolerable, then it is difficult to conclude that the child was harmed by the act which, in giving it deafness, also gave it existence. Sharon Duchesneau and Candy McCullough are seeking to make a deaf baby, not to make a baby deaf. If there is anything objectionable about their attempt, it is submitted, it does not lie with any harm done to the child itself.

How far, though, does this assessment of the Duchesneau-McCullough case answer the broader question of 'harmful choices'? The reliance on the example of deafness, after all,

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[62] K. W. Anstey, 'Are attempts to have impaired children justifiable?' *Journal of Medical Ethics*, 2002; 28: 286-288.

[63] 'the limitation of opportunity here [in the case of deafness] is not inherent in the sense of residing solely in the impairment: to be understood as a limitation of opportunity, there must be a social expectation that the activity that is limited ought to be performed.' Ibid, at p.286.

might be thought to be taking an easy option, given the controversy at the heart of this case as to whether deafness is in fact a disability. The choice of a deaf child would indeed be unproblematic if it were accepted that deafness is unlikely to impact deleteriously on the child's quality of life – but what of more uncontroversially deleterious conditions? It may be straying into the realm of horror fantasy to suggest that a parent would deliberately choose to have a child affected by cystic fibrosis, for example. But with suggestions of genetic predispositions toward aggression, or certain sexual preferences,[65] it is perhaps prudent to imagine future disputes about what constitutes saddling a child with a harmful condition.

Yet the argument being advanced here does not rely on any particular position as to the effects of deafness, or aggression, or sexual preferences, on a child's life. Although there are certain to be controversies at the margins of defining harmful conditions, it is not at all implausible that there are some genetic traits that will have a predictably positive or negative impact on the quality of life of those affected by them. Buchanan, Brock, et al refer to 'natural primary goods', capacities such as sight that are 'useful or valuable in carrying out nearly any plan of life.'[66] Irrespective of the provisions society made to allow blind people to function and interact with a minimum of danger and inconvenience, there are no – or almost no – imaginable societies in which being blind would be anything other than a disadvantage.[67]

Yet the Non-Identity Principle, it is submitted, does not require a comparison between life with sight and blind life, but rather, between blind life and no life at all. Whatever the disadvantages and frustrations of blindness, the possibility of sighted life was never available for the child which is chosen to be blind. The only way in which such a child could be said to be harmed would be if we concluded that being born without sight was worse than never being born at all. As Melinda Roberts reminds us, the 'sole means of

[64] Ibid, at p.287.
[65] See, for example, the theories expounded in Dean Hamer and Peter Copeland's *Living With Our Genes*, London, Pan Books, 2000.
[66] Buchanan, Allen; Brock, Dan W.; Daniels, Norman; Wikler, Daniel. *From Chance to Choice: Genetics and Justice*. New York, Cambridge University Press, 2000, at pp. 167-168.
[67] In a somewhat similar vein, Joel Feinberg has written of 'The Child's Right to an Open Future'; in Aitken and LaFollette, eds., *Whose Child? Children's Rights, Parental Authority, and State power*, Totowa, New Jersey, Rowman and Littlefield, 1980.

saving the baby from the effect of the disorder ... is to refrain from bringing the baby into existence to begin with.'[68]

The Non-Identity Principle renders it meaningless to speak in terms of harming a future child where:

- the 'harmful' act is an indispensable condition of the child's coming into existence at all – a so-called 'genesis act'; and
- the child has a minimally worthwhile quality of life.

It leaves open, however, the possibility that a child could be harmed by a 'genesis act' where that minimal standard of quality of life is not attained. This possible exception, and the implications for the law arising from it, will be considered later in this chapter.

3.3.4 Voices of dissent: Person-affecting objections

The contention advanced so far in this chapter, then, is that following the Non-Identity Principle, only those children born into lives so wretched that non-existence would be preferable have a complaint against those who brought them into existence. Where a handicapped but worthwhile life was the only life available to that child, it simply cannot claim to have been harmed by the acts that bestowed that life upon it.

As will be discussed below, the majority of opponents of the Genetic Supermarket accept the Non-Identity Principle, and do not direct their objections at alleged harms to the children actually born. As will be seen, their opposition generally derives either from Non-Person-Affecting concerns, or from perceived negative externalities. However, for the sake of completeness, there are perhaps a couple of perspectives from which the GS could be criticised, and objections like the *Parental Pressure*, *Resentment* and *Harmful Choice Problems* salvaged, without abandoning the Person-Affecting Principle.

3.3.5 The 'No Trade Offs' View

[68] Melinda Roberts, 'Present Duties and Future Persons: When Are Existence-Inducing Acts Wrong?', *Law and Philosophy* (1995); 14(3/4): 297-327, at p.316.

James Woodward has taken issue with the idea that gains and losses can be offset in the manner implicit in the Non-Identity Principle. While conceding that cases exist where the benefits of existence can be said to outweigh the harms brought about thereby, he questions whether this is sufficient justification for such harms. Interests, Woodward argues, are not fungibles that can be traded off against one another, or factored into a single calculation of 'overall well-being.' Rather, he maintains,

> people have relatively specific interests (e.g., in having promises kept, in avoiding bodily injury, in getting their fair share) that are not simply reducible to some general interest in maintaining a high overall level of well-being and ... many moral requirements function so as to protect against violations of such specific interests. That an action will cause an increase in someone's overall level of well-being is not always an adequate response to the claim that such a specific interest has been violated.[69]

By way of illustration, Woodward offers the following hypothetical example:

> Suppose that Smith, who is black, attempts to buy a ticket on a certain airline flight and that the airline refuses to sell it to him because it discriminates racially. Shortly after, that very flight crashes, killing all aboard. There is a clear sense in which the airline's action has the result that Smith is better off than he otherwise would be, and if selling or not selling Smith the ticket are the only relevant actions which the airline can perform, not selling leaves him better off than any other possible action the airline might have performed. Nonetheless, it seems quite natural to say that the airline's action wrongs Smith.[70]

For Woodward, then, I may wrong someone by an action that leaves him better off than he would have otherwise been, or indeed 'better off than any other action one might have taken',[71] if I have breached a particular obligation that I owed to him.

> We resist the temptation to think just in terms of some single dimension of moral assessment (how well off overall a person is) and to think that if an action affects a person negatively in some respect but has other effects such that the net result is an overall gain (or no total loss) in well-being: moral assessment ought to focus just on this overall outcome.[72]

When applied to Parfit's hypothetical fourteen-year-old girl, this approach allows Woodward to conclude that she will in fact wrong her future child by the very fact of bringing it into existence. Designating the girl 'Alma', Woodward contends that

> Alma knows that if she has a child she will incur certain duties and obligations which she would not otherwise have and which she is very

[69] Woodward, at p.809.
[70] Ibid, at pp.809-810.
[71] Ibid, at p.812.
[72] Ibid, at p.818.

> unlikely to meet adequately. I contend that the failure to fulfil these duties and obligations constitutes an important reason ... for Alma *not* to have a child. If Alma has her child and fails to meet the duties and obligations she owes to her child, the child has a complaint against her, based on a wrong done to the child.[73]

There are two counter-arguments that can be levied against Woodward's contention that Alma has acted wrongly. The first does not involve rejecting Woodward's central premise – that rights and interests (he seems to use the terms interchangeably) are distinct and that their breach or frustration cannot be offset against other gains – but questions precisely which interest or right has been breached in such cases. This counter-argument begins by asking precisely what duties and obligations Alma actually owes to her future child that she is overwhelmingly likely to breach by virtue of her immaturity. We might answer this by reference to any number of obligations that a parent might be thought to owe her children: emotional stability and a minimum standard of economic security being but two. The fact that Alma will foreseeably be unable to meet these obligations would, for Woodward, provide a reason for her to refrain from creating those obligations in the first place.

But what exactly is the nature of the obligation owed by Alma to her future offspring? In particular, is the standard of emotional stability or economic security that she is obliged to provide an absolute or a relative standard? On an absolute standard, it might be argued that she must provide X amount of stability (however we might quantify this) and Y of economic security. Any parent who failed to provide these quantities would derogate from their duties, and the mere fact that they *could* not fulfill them is to be no excuse, for the preferable option in such circumstances would be to refrain from procreating at all.

Yet it is unlikely that many of us regard parental obligations in such terms. Is it Woodward's contention that the 800 million of the world's population who live on less than $1(US) per day act wrongly whenever they procreate? For it is not unreasonable to suppose that a mature woman living in an area beset by famine, war, disease or abject poverty will be worse placed than a fourteen-year-old girl living in the UK to provide emotional stability and economic security for her children. Indeed, the situation is worse

[73] Ibid, at p.815.

for such women, because unlike Alma, they are not merely being required to delay procreation for a few years, but indefinitely.[74]

One way of avoiding this conclusion is to gauge the extent to which parents meet their parental obligations against the extent that it was possible for them to do so. On that relativist analysis, we would judge the extent to which Alma (or the grossly malnourished woman living in abject conditions) fulfilled her duties relative to what it was possible for *her* to have done. Provided the child's life is not of the worse-than-nothing variety, then, we might say that she has breached no obligation to it provided *she does her best* to provide the child with emotional stability and economic security, even if she is, by virtue of her tender years, incapable of providing these things in the same quantities as an older parent might.

A further conception of the duty she owes to her child might say that what she is obliged to provide for her future offspring is as good a life as was possible *for that child*. The Non-Identity Principle holds that, for this child, the only alternative to a life of relative instability and insecurity was no life at all. If Alma's obligation is to provide the best that this child could possibly have, then she might satisfy this even by providing less stability and security than a different child, born to an older Alma, might have enjoyed.

An obligation to provide one's children with as optimal an environment as that child could possibly have enjoyed is actually a very onerous obligation indeed, and we may need to balance this against Alma's other obligations, and indeed her own interests. But again, it becomes clear that it is possible to reconcile Woodward's claim about the specificity of interests or duties with the claim that Alma does no wrong, simply by defining those specific interests and duties in a different way.

The No Trade-Offs view only leads to Woodward's conclusion, then, if we adopt a particular view of the duties Alma owes her child, a view that takes no account of what was possible for Alma, or for this child. This view, as well as being somewhat arbitrary in its selection of duties (an allegation, after all, which could equally be levied against

[74] In fairness, Woodward does claim that Alma's obligations might be different if it were likely to be the case that she would never be able to meet these obligations. But why should this be so? If the obligations owed

any of the other views considered here), might be thought unappealing because it appears to have the consequence of requiring the majority of the world's population to refrain from procreation.

Woodward's objection to the Non-Identity Problem was actually anticipated by Derek Parfit, who proposed a different counter-argument. Parfit does not take issue with the claim that the breach of a particular obligation cannot be defended simply by reference to overall benefit. Nor does he dispute that breaching a duty might be wrong even when it is an indispensable pre-condition of existence itself, conceding that

> The objector might reply: "It is wrong to cause someone to exist if we know that this person will have a right that cannot be fulfilled."[75]

What Parfit does point out is that rights are the sorts of thing that can be waived.

> Suppose that I have a right to privacy. I ask you to marry me. If you accept, you are not acting wrongly, by violating my right to privacy. Since I am glad that you act as you do, with respect to you I *waive* this right. ... This would have undermined our objection to his mother's act.[76]

Since rights can be waived contemporaneously, Parfit maintains, it makes sense to assume that they can be waived retrospectively; and since, if people like Alma's child 'knew the facts, they would not regret that we acted as we did', they 'might waive their rights'.[77] With characteristic intellectual candour, Parfit concedes that this is merely an assumption, and that it is possible that some future people will not regard the violation of their rights as a price worth paying for their existence. For that reason he regards this as only a partial response to the No Trade-Off view.

It may be thought, however, that Parfit is being unduly tentative here. It is by no means certain that the wrongness of an act should be judged retrospectively, according to the subjective perception of another party. For a consequentialist like Parfit, an act that subsequently transpires to produce bad consequences may be a source of regret, but whether it should be a source of guilt or shame or moral opprobrium – whether it could be described as a *morally wrong act* - depends largely on the intent with which it was

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to the child are absolute and not relative to Alma's circumstances, then what difference does it make whether she would be better equipped to provide for a different child in the future?

[75] Parfit, *Reasons and Persons*, op cit, at p.364

[76] Ibid, at p.364

[77] Ibid, at p.365

carried out. If it is reasonably foreseeable that you will regard the violation of your right as a price worth paying for some benefit you accrue (as Parfit puts it, that you will retrospectively waive your right) then it would be unusual to regard that violation as wrongful.

To see that this is normally regarded as so, we need only consider a relatively mundane example. Almost any conception of rights will include some variation of a right to bodily integrity. Yet even among the most ardent proponent of rights, there are few who would claim that I act wrongly when I push you out of the way of the swerving bus. In so doing, I have clearly violated one of your rights, but the anticipated benefit for you – survival or the avoidance of serious injury – is foreseeably great enough to justify my act, in the eyes of almost all ethicists, and indeed of UK law. This will be equally true if, for some reason, you subsequently take exception to my push, claiming that you would have preferred to take your chances with the bus. My act does not become wrongful in retrospect, with the occurrence of some unforeseeable event.[78]

Similarly, while it is, as Parfit acknowledges, theoretically possible that Alma's child might not regard the violation of its rights as a price worth paying for a life that is on balance worthwhile, we might well conclude that this is a turn of events so unlikely as to lie outwith the realm of reasonable foreseeability. Alma is justified in infringing her child's rights to emotional stability and economic security (or, to be more accurate, acting in a way that ensures those rights will one day be infringed) because of her reasonable belief that the child will one day regard that infringement as a price worth paying, just as surely, and for exactly the same reason, as she would be justified in infringing her child's right to bodily integrity by pushing it out of the way of a swerving bus.

3.3.6 The 'Generic Child' View

[78] It does not, however, follow that my competent refusal can be disregarded by a well-meaning surgeon because of his firm conviction that I will subsequently regard his actions with gratitude. As explained in the preceding chapter, the express wishes of a competent person are, in the ordinary case, assumed to be the best indication of what is best for that person. If it were somehow possible to ask Alma's future child its opinion of the trade-off between rights and benefits, then that opinion should guide her action. Since it is not, she has no option but to rely on foreseeable outcomes and probabilities. In this respect, her position is closer to the surgeon who operates on me without my consent when I am unconscious. His invasion of my bodily integrity is deemed justifiable if it was foreseeably in my best interests, and does not subsequently become wrongful if I subsequently respond with unforeseeable hostility to his actions.

Robert M. Green is another writer who has sought to challenge the 'No Difference' conclusion without straying from the realm of Person-Affecting Principles. Green's argument rests on two premises that, if accepted, seem to allow us to conclude that someone is harmed by Alma's decision to become pregnant now:

- the rejection of the comparison between the life her child actually has and the only alternative for it (i.e. non-existence) with a comparison with 'the *reasonably expected health status of others in the child's birth cohort.*'[79]
- the attribution of interests to a 'generic' child, a sort of composite of all the possible children our hypothetical prospective parent might have had.

Green's argument relies on the (uncontested) realisation that, prior to conception, the 'potential future child' of whom prospective parents speak is not a discrete entity at all, but rather, an amalgam of myriad possibilities:

> before conception (for most people) and even following conception during early pregnancy (for many others), lives are in a sense "fungible"; they are interchangeable generic units, rather than identifiable and unique. Parents intending to have a child do not imagine the identifiable child "Mary" who they come to know in the years following her birth, but a "generic" child with qualities like those of most other children being born in its cohort. It is this imagined child whom they usually have in mind in choosing to have a child in the first place, and against whom they and others measure the actual condition of the real child when it is born.[80]

If it is intelligible to speak of a single 'generic child', then it is perhaps intelligible to attribute to that child a unitary set of interests; and it may be intelligible to include among those interests something like an 'interest in being born in the best possible genetic health', or perhaps an 'interest in being born with a minimum standard of genetic health'.

For Green, the required standard would fall between these two poles. He goes considerably further than those like Parfit, who contend only that a prospective parent should stop short of bringing a child into existence who would have a worse-than-nothing life. Rather, he contends, 'we should compare the status of the actual child born with that of the average child in its birth cohort',[81] acting so as to avoid

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[79] Robert M. Green 'Parental Autonomy and the Obligation Not to Harm One's Child Genetically' *Journal of Law, Medicine & Ethics* 25 (1997): 5-15, at p.8

[80] Ibid, at p8. For a similar argument, see Simo Vehmas, 'Is it Wrong to Deliberately Conceive or Give Birth to a Child with Mental Retardation?' *Journal of Medicine and Philosophy* (2002) 27(1): 47-63, at pp.52-53.

[81] Id.

> "significantly greater" suffering or disability than others in the child's birth cohort. ... As a practical measure, we can determine whether harm is significant by asking whether, as a generality, children (or, later, adults) with a specific condition would prefer to have lived their lives free of their specific congenital disorder or disability.[82]

Some of Green's argument seems to rely heavily on the presumed linguistic slackness and conceptual confusion of others. 'This is the appropriate benchmark,' he argues,

> ... because it is the one that most parents are likely to use in deciding whether to have a child in the first place, and it is also the benchmark that the child and those around it are likely to use in assessing the quality of its start in life.[83]

It is noteworthy that although his suggestion derives from an empirical rather than philosophical premise – we should adopt this benchmark because most people do in fact think this way - he offers no sociological evidence to support this. Even assuming the accuracy of his contention, though, it might be thought somewhat illiberal to use the fact that 'most parents' think this way as a justification for forcing the few dissenters who he goes on to discuss to comply. In the absence of some argument proving the superiority of the majority view, this might be thought little more than an example of gratuitous reproductive totalitarianism, forcing a particular view of reproduction on a minority for no other reason than that theirs is not a common view.

Yet not only does Green fail to demonstrate the superiority of his view, he actually concedes, quite explicitly, its paucity of intellectual rigour. In discussing the claim 'If my mother had only waited a few months until after the rubella epidemic had passed to conceive me, "I" would never have been born with this deformity', he concedes that

> Taken strictly, this statement is nonsense: the child who could have been conceived and born after a delay of some months is not the same child as the one who was conceived and born earlier.[84]

The only way to circumvent the absurdity of this position is by

> think[ing] of ourselves before conception or birth as an imaginary fungible intended child of our parents, who could come into being with roughly the same physical and mental attributes as other children, this statement makes perfect sense.[85]

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[82] Ibid, at p9
[83] Ibid, at p8
[84] Ibid, at p8
[85] Id.

These two statements, taken together, reveal that Green's argument is weakened by reliance on what he acknowledges to be a fantasy, in which interests are projected onto an 'imaginary' child, in an attempt to prop up a belief that its chief proponent admits is 'nonsense'. It may well be that disabled children or adults from time to time engage in the sort of speculation he suggests, about how much better 'their' lives would have been had their parents delayed conception. Many of us have daydreamed of alternative lives in alternative times or places that we might have lived. But, as even Green acknowledges, these alternative lives of which we dream would not have been 'our' lives at all.

It should, of course, be noted that jurisprudential and philosophical reasoning have a long and respected tradition of reliance on imagined entities, from Hobbes' Leviathon to Nozick's Utility Monsters. Green's reference to a 'generic' child and 'an imaginary fungible intended child of our parents' bears some superficial similarities to one such fantastic entity: John Rawls' ideal lawmaker, peering out through the 'veil of ignorance'.[86] In this famous thought experiment, Rawls imagined a lawmaker passing laws from a position of ignorance as to which position he would occupy in the world.[87] If he did not know whether he would be a prince or a pauper, then his decisions as to what the law should be were unlikely to be unfairly skewed in the interests of either princes or paupers, but would be designed so as to produce the best outcome for the lawmaker irrespective of the role he is allocated. (For Rawls, in fact, the logical lawmaker would act so as to level out the inequalities in society, thereby ensuring that whatever role he was allocated would not be intolerably bad.)

It is possible that Green had something of this nature in mind when he conceived of the 'generic child', which is also a sort of pre-existence entity that could view all of the possible lives into which it could be born. However, unlike Green, Rawls never seriously sought to argue that such an entity actually existed; rather, this was an imagined ideal to which the just lawmaker ought to aspire. If the lawmaker transpired to be less than just, Rawls at no time argued that this would be bad for the being that exists behind the veil of ignorance. His decisions would be bad because they were bad for others, or bad because they were unjust. The imagined veil of ignorance serves as a useful device insofar as it

[86] John Rawls, *A Theory of Justice. Revised Edition.* Oxford, Oxford University Press, 1999.

provides us with a mechanism whereby we can act so as to further these other ethical objectives. Unlike Green's generic child, though, the pre-existence lawmaker who dwells behind it has no interests of its own, and no intrinsic worth beyond its value as a decision-making device.

3.3.7 Person-Affecting Objections: Summary

The ethical basis spelt out thus far would appear to give no reason whatever for preferring to implant Embryo X rather than Embryo Y. This is so because, despite the fact that Person X is likely to have a much higher quality of life than Person Y, the decision to bring about the existence of the latter cannot be shown to be contrary to the interests of a particular person. Person Y, after all, has 'a life that is better than no life at all,'[88] and the only alternative for him would have been non-existence; the 'sole means of saving the baby from the effect of the disorder ... is to refrain from bringing the baby into existence to begin with.'[89] As discussed above, we have no duty to bring Person Y into existence. Having done so, however, we have no alternative but to consider the effect of that act on Person Y by reference to the whole package of harms and benefits that life brings him.

Person X, meanwhile, has no interests and never will have any interests to be frustrated since, in this scenario, she will never exist. Those who accept Heyd's generocentric version of the utilitarian moral axiom may find this conclusion quite acceptable; if concern in ethical matters should be restricted to the interests of 'actual' persons, present or future, then the failure to create a more rather than less worthwhile life may be seen to be of no consequence. On such a view, the only interests to be weighed up[90] in deciding how the GS should be regulated are those of the prospective mother and those third party interests which will be considered later.

However, for those who find this perceived moral neutrality of the woman's choice to be unsatisfying, it would seem that some argument must be advanced for the implantation of Embryo X rather than Embryo Y which relies on something other than frustrating the

[87] The lawmaker would, of course, be able to suppose that he would not fall into that category of beings who are unable to consider the very question that s/he is presently considering. To paraphrase Descartes, 'I think, therefore I am, at a minimum, the kind of being that can think.'
[88] Dan Brock, 'The Non-Identity Problem And Genetic Harms - The Case Of Wrongful Handicaps', *Bioethics* (1995) 9(3/4):269.
[89] Roberts, op cit, at p316.
[90] Assuming that no embryo exists which would lead to a person with a life worse than non-existence.

interests of particular persons, an argument which rejects the claim that a 'wrong act must be bad for someone.'[91]

3.4 Non-Person-Affecting Objections

I have argued, then, that the Non-Identity Principle renders it intelligible to speak of harming a potential future child by a genesis act only in those rare cases where its life is foreseeably so awful as to constitute a harm in itself. Does this, then, conclude the question of future children? For the majority of commentators in this area, the matter cannot be left there; the conclusion that implanting a disabled embryo rather than a healthy one is a matter of ethical indifference – what Parfit called the 'No Difference' conclusion – is too counter-intuitive to be accepted. However, the majority of commentators also accept the Non-Identity Principle, thereby presenting them with the problem of identifying who precisely is the subject of harm.[92]

For such writers, the only way to establish a harm resulting from such choices is by moving away from Person-Affecting approaches and seeking to ground their arguments in Non-Person-Affecting (NPA) concepts of harm. This was what Parfit attempted by his "*The Same Number Claim*, or *Q*."[93] This view he describes as follows:

> If in either of two possible outcomes the same number of people would live, it would be worse if those who lived are worse off, or have a lower quality of life, than those who would have lived.[94]

Similar NPA principles have been suggested by Joel Feinberg,[95] Buchanan, Brock, et al,[96] and by Julian Savulescu.[97] As Buchanan, et al, explain,

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[91] Brock, op cit..

[92] ~~Get ref.~~ Buchanan, Allen; Brock, Dan W.; Daniels, Norman; Wikler, Daniel. *From Chance to Choice: Genetics and Justice*. New York, Cambridge University Press, 2000, at p.225; Philip G. Peters, Jr., 'Harming Future Persons: Obligations to the Children of Reproductive Technology.' *Southern California Interdisciplinary Law Journal* (1999) 8: 375-400, at p.399; Julian Savulescu 'Procreative Beneficence: Why We Should Select the Best Children' *Bioethics* (2001) 15 (5/6): 413-426, at p.418.

[93] Parfit, op. cit., at p360.

[94] Id.

[95] 'The wrongdoer in the example must be blamed for wantonly introducing a certain evil into the world, not for inflicting harm on a person.' *Harm to Others*, op. cit., at p103.

[96] Their version of a NPA principle is referred to as 'N', and states that:

> Individuals are morally required not to let any child or other dependent person for whose welfare they are responsible experience serious suffering or limited opportunity or serious loss of happiness or good, if they can act so that, without affecting the number of persons who will exist and without imposing substantial burdens or costs or loss of benefits on themselves or others, no child or other dependent person for whose welfare they are responsible will experience serious suffering or limited opportunity or serious loss of happiness or good.

> this principle for the prevention of suffering applies not to distinct individuals, so that the prevention of suffering must make a distinct individual better off than he or she would have been ... but to the classes of individuals who will exist if the suffering is or is not prevented ... [98]

While it would still, then, be true that no distinct individual is harmed if the disabled embryo is implanted, the subject of harm can be seen as

> the classes of all persons who will exist in each of two or more alternative courses of action will be a non-person-affecting principle.[99]

This view might seem very close to that espoused by Robert Green, and considered (and ultimately rejected) in the preceding section. However, the NPA approach differs from that of Green in several important respects. Green, for example, sought to keep his argument within the confines of the Person-Affecting Principle, by speaking of one Generic Child, an amalgam of all the possible future children that the prospective parents might have. The person to whom the harm might be done, then, is this fungible, composite Generic Child.

The NPA apparoach, in contrast, purports to make no such attempt at identifying a particular person (notional or otherwise) who is the subject of harm, but relies instead on the purportedly shared interests of that group of potential future persons. As such, it is not subject to the criticism that was levied at Green; namely, that he relied upon an admittedly fictitious entity for a subject of harm. There clearly *are* a number of potential future children who could arise from the GS, and to speak of them as a 'class' is not obviously nonsensical in the manner of Green's Generic Child.

It is submitted, however, that the NPA objections to the GS are themselves ultimately unsatisfactory, for at least two distinct reasons. First, doubts may be expressed about the NPA's reliance upon a notional class of potential beings with a collective pool of interests. There are, of course, myriad circumstances in which it is quite accurate to refer

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Buchanan, Allen; Brock, Dan W.; Daniels, Norman; Wikler, Daniel. *From Chance to Choice: Genetics and Justice*. New York, Cambridge University Press, 2000, at p.249.

[97] Savulescu has argued for a Principle of Procreative Beneficence, which would maintain that: couples (or single reproducers) should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as the others, based on the relevant, available information. Julian Savulescu, 'Procreative Beneficence: Why We Should Select the Best Children' *Bioethics* (2001) 15 (5/6): 413-426, at p.415

[98] Buchanan, Allen; Brock, Dan W.; Daniels, Norman; Wikler, Daniel. *From Chance to Choice: Genetics and Justice*. New York, Cambridge University Press, 2000, at p.249

[99] Id.

to classes of individuals having collective interests. A footballer may resent being substituted in an important match, but his manager may justify this as being in the interests of the team. If the player accepts this, it is because he identifies his own interests with the team's ultimate success; his individual interest in staying on the pitch coexists with the collective team interest, of which others of his individual interests form a part.

There is nothing linguistically or logically incoherent about referring to X and Y as belonging to the class of potential future beings. What is problematic is seeking to attribute to that class a set of shared interests, analogous with that of a football team, which can be furthered or frustrated by the implantation choice. Quite simply, only one of the rivals for implantation will ever attain any interests whatever – a fact that Buchanan, et al, specifically acknowledge.[100] As discussed earlier in this chapter, the rejected embryo cannot be said to be harmed or benefited by the decision to reject it. The choice between X and Y is simply a choice between which of two different sets of interests we will bring into existence. To speak of the two as having a shared pool of interests flies in the face of this reality. The notion that we can owe duties to the class of possible children we might have, I submit, is tempting only in the linguistic sense, relying as it does on the false aggregation of intrerests which cannot co-exist.

A rather different conception of the NPA principle has been advanced by writers such as Harris and Feinberg. While both explicitly recognising that the disabled child will, in all but the rarest scenarios, have no cause for complaint, both agree that the mother who chooses a disabled over an able-bodied child still acts wrongly. For Feinberg, the wrong lies in 'wantonly introducing a certain evil *into the world*, not for inflicting harm on a person',[101] while in almost identical terms, Harris speaks of 'the wrong of bringing avoidable suffering into the world, of choosing deliberately to increase unnecessarily the amount of harm or suffering in the world or of choosing a world with more suffering rather than one with less.'[102]

[100] Buchanan, Brock, et al, *From Chance to Choice*, op. cit., at p.236
[101] Feinberg, *Harm to Others*, op. cit., at p103, emphasis added.
[102] Harris, *Wonderwoman and Superman*, op. cit., at p90.

On the face of it, an ethical principle that imposes impersonal duties to *the world* is tempting for those who are dissatisfied by the No Difference conclusion, as it obviates the need to identify a particular person – actual, potential or notional – who is the subject of the harm. It would allow us to conclude that the 14 year-old girl, as well as Candy McCullough and Sharon Duschesneau, acted wrongly, even though the children that they brought into the world have no grievance against them.

However, on closer examination, it seems that the 'duty to the world' approach is itself problematic. This becomes apparent when we consider that a duty to the world – at least in the vaguely utilitarian sense advanced by Harris and Feinberg - must take one of two forms. The first involves a duty to minimise the amount of suffering in the world, regardless of any offset against happiness (referred to here as the *No Suffering* view. There is a suggestion, perhaps, that this is what Harris is thinking of when he refers to the wrong of 'choosing a world with more suffering rather than one with less.'[103])

If the duty took this form, then it would make sense to say that the mother of the disabled child does wrong when she goes ahead with the pregnancy, because the child she has – although benefited overall – will live a life containing more suffering than the alternative child that she could have had, and therefore, her choice causes more rather than less suffering in the world. That this view is problematic, however, becomes clear when we consider that it seems to lead to the conclusion that *anyone* would do wrong when they bring *any child* into existence. Every life involves some degree of suffering, and while we ordinarily regard this as being offset by the amount of happiness/enjoyment/satisfied desires in those lives, the *No Suffering* view appears not to allow us any such trade-off.[104]

The ethical imperative to minimise the amount of suffering in the world, then, could best be achieved by having no children at all, and anyone who chooses to have a child in the knowledge that its life will contain some degree of suffering seems to violate this imperative.[105]

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[103] Id.

[104] A point eloquently expressed by S. D. Edwards in 'Prevention of disability on grounds of suffering', *Journal of Medical Ethics* (2001); 27:380-382, at p380.

[105] It is also, perhaps, interesting to note that the *No Suffering* conception of the NPA principle would seemingly find no objection to the deliberate creation of an anencephalic or otherwise asentient child.

Alternatively, we may recognise a duty to the world that is slightly more complex than the *No Suffering* view, requiring instead that we do indeed offset the suffering we introduce into the world against the happiness we introduce. A duty to maximise the amount of happiness-over-misery in the world – referred to here as the *Aggregate* approach - would provide us with a reason to say that the actions of the 14 Year-Old Girl and Duschesneau and McCullough are wrong *only if* there was an alternative course of action open to them that would have produced a greater aggregate of happiness-over-misery in the world.

Since, in Parfit's scenario, the 14 Year-Old Girl has the option to delay pregnancy until such time as she can give her child a better start in life, and since Duschesneau and McCullough could certainly have had a child that was not (or had a much lower likelihood of being) deaf, they acted wrongly when they elected to act as they did. But had those children been the only children to whom they could possibly have given birth, then – assuming the lives of those children contain *some* balance of happiness over misery – then they have not offended the *Aggregate* principle.

It is easy to imagine how this version of the NPA principle might seem more moderate, and hence more appealing, than the *No Suffering* view. However, I would submit that it gives rise to conclusions that are no less implausible than the latter. For, as distinct from the *No Suffering* view, the *Aggregate* view contains not only an obligation to minimise suffering in the world, but a symbiotic obligation to maximise happiness (perhaps conceived of in terms of satisfied interests). Note that this is distinct from an obligation to satisfy existing interests; rather, the obligation implicit in this version of the axiom is to create satisfiable interests *ab initio*, in order that they might be satisfied.

The obvious problem here is that such a principle regards as ethically wrong not only the decision to create a less-than-optimally-happy baby, but would also regard as wrong the decision to refrain from having a child at all. After all, the individual who elects to remain childless when the option of having a reasonably happy child was open has failed in her duty to maximise the amount of happiness-over-suffering in the world.

To say otherwise would be to adopt the rather strange position of denying that a woman is subject to any kind of moral obligation to increase the overall 'happiness' by

reproducing, but that having voluntarily elected so to do, she suddenly becomes subject to a more onerous obligation to increase the overall happiness *to as great a degree as possible* by having a particular kind of child. This may be seen as analogous with an argument which claimed that, while no-one is under any obligation to donate money to charity, those who voluntarily elect to give a little will be forced to give as much as possible.

Furthermore, it may be seen that the *Aggregate Principle* imposes a duty to reproduce to the optimum degree, or at least up to the point where each additional child would cease to yield a marginal gain to 'the world' in terms of happiness. That is to say, there may come a point where poverty or overcrowding meant that the birth of an extra child would actually decrease the happiness balance, because its life would be of a low quality, while its birth would impact detrimentally on the lives of its siblings. Nonetheless, until that point is reached, and while the birth of each successive child contributes positively to the happiness-over-misery balance sheets, it is difficult to see how the reproductive imperative can be avoided.

Several writers have attempted to avoid this conclusion by claiming that the effect upon the quality of lives of individuals coerced into having unwanted children would be so severe as to render this argument redundant,[106] while others have argued that the act of procreation constitutes an inefficient use of resources which could, from a utilitarian view, be better spent improving the lives of existing persons - the so called Argument From Transfer.[107] However, neither argument is entirely convincing. The claim that forcing reluctant parents to procreate would cause more harm than good seems dubious; if the reluctant parents still have worthwhile, albeit diminished, lives, it is difficult to see

[106] See, e.g., Glover, *Causing Death and Saving Lives*, op cit, at p.70.

[107] Christian Munthe, 'The Argument From Transfer', *Bioethics* (1996) 10(1); 26-42. It should be noted that Munthe's argument does not rely upon a belief that concern should be restricted to actual persons, nor indeed does it require a belief that the interests of actual persons be accorded priority over those of potential future persons. Rather, his claim is based upon the reasoning that, while creating a worthwhile life involves an improvement in overall utility of +1, there are in existence a considerable number of persons whose lives are in fact so bad as to be subjectively worse than non-existence, and to whom we could accord a utility rating of -1. Obviously, if it were possible to render these existing lives subjectively valuable by using the resources which would have been spent on a new person, this would be the better course of action, since the improvement from -1 to +1 is greater than the improvement from 0 to +1. His argument, of course, depends for its success upon the assumptions that (i) there are in existence significant numbers of persons whose lives are worse than non-existence, and (ii) that these lives could be made worthwhile by the deployment of the resources which would otherwise have been spent upon procreation.

how their loss could outweigh the gain in overall utility brought about by the creation of another worthwhile life.[108]

The Argument From Transfer, meanwhile, seems only to discharge from the duty to procreate those who redirect that time and effort which would have been spent on the new child to improving the lot of those leading the most miserably unfulfilled lives. While there is nothing logically wrong with this view, those who consider this burden to be unduly onerous must concede that the Argument From Transfer does not constitute a valid defence of the *Aggregate Principle*.

The application of Non-Person Affecting principles, of the type advocated by Harris and Feinberg, to the area of human reproduction seem destined to be acceptable only to those who concede either (a) that all potential parents can be subject to a duty to reproduce, and continue reproducing up the point where their own or the children's lives would be miserably wretched, or (b) that all potential parents should refrain from reproducing at all, since every life contains *some* degree of suffering. Since it seems safe to assume that both of these conclusions would be ridiculous or repugnant to most readers, it is submitted that NPA principles are unsatisfactory, and that instead, we should concentrate on the effect of PGD and the Genetic Supermarket on actual individuals, current or future.

3.5 'Worse Than Non-existence' lives

I have suggested in this chapter that the Non-Identity Principle made it impossible to argue that a child was harmed on balance by a decision on which its very existence was contingent, but noted at that time that a possible exception could exist for those cases where the experiential existence of that child is such as to allow us to deem it worse than non-existence, or worse than nothing (WTN). Such a judgement could be made where the child's most important interests are doomed from the outset – such as its interest in avoiding intolerable suffering – while at the same time no corresponding interests could be furthered.

[108] See Stuart Rachels, 'Is It Good To Make Happy People?', *Bioethics*, (1998) 12(2); at p109.

Since predictable future interests constitute a valid, indeed unavoidable, cause for concern, it may be said that, in electing to implant a 'doomed embryo', a course of events is set in motion which will result in a predictable future harm, just as surely as when the broken glass is carelessly discarded in the woods. The harm in question, though, will not be a cut foot, but rather a life of such wretched quality that, from the subjective perspective of the child itself, it would have been better never to have been born.

Examples would almost certainly be rare, but we might plausibly consider that the lives of those affected by genetic disorders that guarantee brief, severely cognitively impaired and pain-filled lives might be so considered. Consider, for example, Philip Kitcher's description of the progress of Lesch-Nyhan syndrome:

> an allele on their single X chromosome causes boys to suffer mental retardation and extreme physical pains of the type associated with gout. Yet perhaps the most disturbing feature of the condition is an apparently irresistible urge to self-mutilation - the boys chew their lips and the tips of their fingers until they are raw and bleeding. At present, doctors can relieve some of the gouty symptoms, but they are unable to prevent the mental retardation and can only block the compulsive mutilation by applying bandages to hands and lips.[109]

There is, I submit, a strong argument for concluding that such lives are 'worth not living'; they contain constant pain which cannot be entirely relieved, a compulsion to self-mutilate which can only be controlled by restraining the child, and - in view of the severe retardation, behavioural disorders and short life expectancy - no real opportunity for compensatory pleasures or satisfied interests of any sort. 'There is nothing to be done,' Kitcher observes, 'except to alleviate pain and discomfort, no aspirations we can expect to foster, no plans, however humble, to bring to fruition.'[110]

UK law adopts a somewhat ambivalent attitude to the prospect of WTN lives. In the context of non-treatment decisions involving infants, the courts have been willing to recognise that a child's life is so subjectively unpleasant as to make it impossible to regard life-prolonging treatment as being in that child's best interests. In *Re B (a minor) (wardship: medical treatment)*,[111] Lord Templeman was willing to confront this issue head on. It was the duty of the court, he stated,

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[109] Philip Kitcher, *The Lives to Come*, Allen Lane The Penguin Press 1996, at p82.
[110] Ibid, at p288.
[111] (1981) 3 All ER 927

> to decide whether the life of this child is demonstrably so awful that in effect the child must be condemned to die or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die.[112]

In this particular case, the court concluded that the child's condition was not such that life-sustaining treatment would necessarily achieve no more than the prolongation of suffering. However, Lord Templeman went on to make it quite clear that there may be other circumstances where

> the future [of the child] is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion.

Indeed, in several cases subsequent to *Re B*, the courts *did* reach different conclusions as to the requirement to prolong life, and in each of those the principle that, occasionally, life can be a burden rather than a benefit was restated. In *Re J (a minor) (wardship: medical treatment)*,[113] Lord Donaldson, M.R., acknowledged the 'very strong presumption in favour of a course of action which will prolong life', but added that this presumption 'is not irrebuttable.' On the contrary,

> account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged ... In the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurate benefit[114]

Indeed, at least one lower court judge has been willing to recognise a positive interest held by an infant in being allowed to die. In the much-publicised conjoined twins case,[115] Johnston, J. claimed that

> the few months of Mary's life if not separated from her twin would not simply be worth nothing to her, they would be hurtful. ... To prolong Mary's life for these few months would in my judgment be very seriously to her disadvantage.[116]

The courts have, however, displayed a marked reluctance to require such evaluations to be made prospectively. In the one and only 'wrongful life' case to be heard in the UK,

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[112] Ibid, per Lord Templeman, at p929.
[113] [1991] Fam 33.
[114] Ibid, at p.46.
[115] *Re A (children) (conjoined twins: surgical separation)* [2001] 57 BMLR 1
[116] Ibid, at p10. The claim that Mary's life would be 'hurtful' to her might, however, be thought difficult to reconcile with Johnston J.'s comment on the preceding page that 'There is no way that could remotely be described as reliable by which those tending Mary can know even now whether she is hurting or in pain.'

McKay v. *Essex Area Health Authority*,[117] the Court of Appeal refused to attempt a comparison between a particular quality of life and non-existence, Lord Justice Stephenson expressing this reluctance in the following terms:

> The only loss for which those who have not injured the child can be held liable to compensate the child is the difference between its condition as a result of their allowing it to be born alive and injured and its condition if its embryonic life had been ended before its life in the world had begun.[118]

It is interesting to note that the Lords of Appeal seem to have enjoyed a firmer grasp of the Non-Identity Principle than the members of the HFEA showed when discussing PGD or tissue typing.[119] Stephenson, LJ continued:

> But how can a court of law evaluate that second condition and so measure the loss to the child? Even if a court were competent to decide between the conflicting views of theologians and philosophers and to assume an "after life" or non-existence as the basis for comparison, how can a judge put a value on the one or the other, compare either alternative with the injured child's life in this world and determine that the child has lost anything, without the means of knowing what, if anything, it has gained?[120]

In a similar vein, Ackner, LJ asked:

> But how can a court begin to evaluate non-existence, "the undiscovered country from whose bourn no traveller returns?" No comparison is possible and therefore no damage can be established which a court could recognise.[121]

This is a curious contention, and, it may be thought, an even more curious choice of quotation with which to illustrate it. The reference to the 'undiscovered country' comes from Hamlet's soliloquy on contemplating suicide, and its context makes it entirely clear that it refers to *death* and not to non-existence:

> Who would fardels bear, to grunt and sweat under a weary life, But that the dread of something after death, The undiscover'd country from whose bourn no traveller returns ...[122]

Can it really be Ackner LJ's contention that no meaningful comparison can be attempted between death and life? This would certainly fly in the face of the rationale of the non-

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[117] [1982] Q.B. 1166.
[118] Ibid, at p1181.
[119] Even clearer evidence of this understanding can be found at p1182, per Stephenson LJ.: 'If a court had to decide whether it were better to enter into life maimed or halt than not to enter it at all, it would, I think, be bound to say it was better in all cases of mental and physical disability, except possibly those extreme cases already mentioned ... but certainly not excepting such a case as the present.' See also Ackner, LJ., at p1189
[120] Ibid, at p1181, per Stephenson, LJ.
[121] Ibid, at p1189.

treatment cases considered above. The only way to make sense of non-treatment decisions (and of the damages awarded for '[l]oss of expectation of life', referred to by Stephenson, LJ[123]) is by demonstrating that wrongful life claims are asking the courts to consider, in non-existence, something that is not only *different* from death, but somehow more difficult to quantify or compare. In this, it may be seen the Lords of Appeal were less than wholly convincing. Certainly, Stephenson, LJ's claim that

> In measuring the loss caused by shortened life, courts are dealing with a thing, human life, of which they have some experience; [in the wrongful life case] the court is being asked to deal with the consequences of death for the dead, a thing of which it has none.[124]

appears to offer scant support for the distinction. It simply is not true that wrongful death cases involve only a knowledge of life, nor that wrongful life cases involve only a knowledge of 'the consequence of death for the dead'. Rather, both – and we may also involve non-treatment decisions in this – involve comparisons *between* existence and non-existence.

To award damages on the basis that someone has lost out by being deprived of life necessarily involves some tacit assumptions about what death involves, and those assumptions seem to be that death is, ordinarily, worse than further life. It is obviously true that neither judges nor anyone else has personal knowledge of what that 'undiscover'd country' involves, but no decision about whether to allow a handicapped neonate to die could be meaningful without some means to effect a comparison between the alternatives on offer. If such assumptions, unsubstantiated by evidence, are possible in relation to non-existence states after death, there is no obvious reason why similar assumptions could not be possible in relation to non-existence states prior to birth.

It may, indeed, be true that – as Stephenson, LJ suggested[125] – in many cases, an accurate prediction of the future child's state will be extremely difficult in advance of its birth. This, though, is an evidentiary problem, and if it were shown that the extent of the child's suffering was not foreseeable at the time of the implantation decision, then this would presumably constitute a defence against either a criminal charge under s.13(5), or a civil suit for wrongful life. However, this difficulty provides no principled basis to distinguish

[122] *Hamlet*, Act 3, Scene 1.
[123] [1982] Q.B. 1166, at p1181.
[124] Id.

the task before the court in a wrongful life suit from the equally galling tasks it faces in non-treatment and other decisions;[126] in both cases, assumptions must be made about the subjective experiential existence of an entity that will sometimes have no means of communicating its feelings.

Attaching a notional value to non-existence is undeniably problematic, but it is as necessary for any comparison between life and death (which courts make on a regular basis) as it is for a comparison between life and never existing (which the Court of Appeal steadfastly refused to undertake). While Stephenson, LJ was almost certainly right to rule that it could not be suggested of the child in *McKay* that 'the quality of her life is such that she is certainly better dead',[127] even this observation seemed to sit uncomfortably with his contention that no such comparison was possible.

Even less easy to reconcile is the judicial reluctance to attempt such comparisons, and the willingness of Parliament to impose a duty on providers of reproductive technologies to do exactly this. Section 13(5) of the 1990 Act specifically requires a consideration of the welfare of the future child prior to the provision of such services. Since it is presumably unlikely that Parliamentary intent was that such a consideration should have no bearing on the decision whether to provide treatment, it seems obvious that the intention was that certain welfare considerations would lead to the refusal of such treatment.

Implicit in such a provision is the assumption that, in certain circumstances, it is foreseeably in the interests of a potential future child to be spared existence, or that the life of such a child, were it to be created, would contain such a balance of harms over benefits that its life would constitute a 'harm on balance'.[128] Thus, a burden has been

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[125] Ibid, at p1180.

[126] A point made by Robert Lee in 'To be or not to be: is that the question? The claim of wrongful life', in Lee and Morgan, eds. *Birthrights: Law and Ethics at the Beginnings of Life*, London, Routledge, 1989, at p177.

[127] Ibid, at p1180. The child was deaf and partially blind as a result of contact with the rubella virus.

[128] Lee and Morgan have claimed that, by avoiding mention 'of any requirement that the welfare of that child be considered as paramount', Parliament 'at least saved the workings of the section from a philosophical appreciation of existence against non-existence.' Robert G. Lee and Derek Morgan *Human Fertilisation & Embryology: Regulating the Reproductive Revolution*. London, Blackstone Press Limited, 2001, at p.164. Although the absence of such a paramountcy requirement may have some significance in tissue typing cases – see Chapter 5 – it is unclear how this obviates the need for such a comparison, or with confronting the NIP. Considering the welfare of the future child before providing treatment services can only be a meaningful requirement if it is envisioned that, in some cases, this will lead to a decision – motivated by concern for that

placed on infertility clinics that the Court of Appeal deemed too onerous to assume for itself.[129]

What, then, would constitute a proportionate and consistent approach to WTN lives? Given the predictability of the phenotypical manifestations of certain genetic conditions, it may be that the judges in *McKay* were unduly reticent about attempting a comparison between a life of *any* quality and non-existence. Indeed, we may well be sceptical about the disanalogy between death and non-existence, upon which the distinction between non-treatment and wrongful life cases rests.

Perhaps more compelling is John Harris's observation that wrongful life actions, even if successful, do not extinguish the harm of a WTN life. After all, he observes, if monetary compensation raises the quality of life, from the child's subjective perspective, above the threshold of a life worth living (or at least a life *not* worth *not* living; an anencephalic neonate, for example, we might consider to have no interest in whether it lives or not) then their lives were only 'only contingently worth not living',[130] i.e. it was their economic circumstances as well as their genetic condition that rendered their lives so wretched.

This seems a valid observation, but it is also possible that a wrongful life payment, while perhaps not raising the life in question above the threshold, will raise it *to an extent*, rendering it slightly less intolerable for the child concerned. If WTN can be counted as 'less than nothing', then there is no reason why we cannot designate some as further below that baseline than others. Nonetheless, provided even a successful wrongful life action would leave the child in the WTN category, it is difficult to disagree with Harris's conclusion that, in such cases, the appropriate remedy would be euthanasia.[131] Since UK law continues to uphold its (almost) absolute prohibition on active killing, even in cases

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child's welfare – not to provide such services. This, I suggest, inevitably involves a comparison between the child's likely welfare if born, and the alternative for that child, i.e., non-existence.

[129] Though, as Lee and Morgan note, 'there seems to have been relatively little overt resistance from doctors disclaiming the capacity to make the social assessments required by s. 13(5)', this does not detract from the inconsistency of requiring them to do what the Court of Appeal has effectively ruled impossible. Ibid, at p.165.

[130] Harris, *Wonderwoman and Superman*, op. cit., at p.96.

[131] Id. See also Patricia M.A. Beaumont, 'Wrongful Life and Wrongful Birth', from *Contemporary Issues in Law, Medicine and Ethics* ed. Sheila A.M. McLean, at p.112.

where this may be thought to be in the individual's interests,[132] euthanasia will not be a practical solution. However, in those cases where the WTN infant requires life-sustaining medical treatment (which we might assume will all but invariably be the case) the judgments in *Re B*, et al, will allow for a decision that will expedite the child's death. (Although the recent European Court decision in *Glass v UK*[133] recognises the familial right to be consulted, it would not allow the parents of a WTN child to demand that its life be prolonged when this was manifestly contrary to the child's interests.)

From a harm-avoidance perspective, however, the ethically preferable outcome is that such lives should not come into existence at all, or should not develop to the point of acquiring sentience; preventing suffering, after all, is preferable to ending it once it has begun. A requirement that prospective parents avoid creating such lives would impact significantly on their interests in reproductive liberty, as discussed in Chapter 2, and would harm those (presumably very few) who either wished to create such children,[134] those who sought to forego screening altogether, and those who merely feel aggrieved at the curtailment of what they believe should be exclusively their choice. However, it may be legitimate to regard such a harm as outweighed by the harms sustained during its brief sentient existence by a child affected by a WTN life.

This, in view of the Non-Identity Principle, would be the one intelligible, child-oriented application of s.13(5). A narrow construction of the welfare test would require fertility clinics to refuse treatment only in those cases where it is foreseeable that the life of the resulting child would be subjectively WTN. Since many genetic conditions vary in terms of penetrance, meaning that it is often impossible in individual cases to make an accurate pronouncement on the quality of a life until the child is born (and perhaps not until some time thereafter), it might be anticipated that the range of conditions to which s.13(5) would actually apply would be narrow indeed. Certainly, it could not meaningfully be

[132] *R v Director of Public Prosecutions, Secretary of State for the Home Department, ex parte Diane Pretty* [2002] 1 AC 800

[133] *Glass v United Kingdom* (61827/00) [2004] 1 F.L.R. 1019

[134] This presumes that, unlike Feinberg, we do not exclude from our ethical considerations those interests which he deems inherently immoral, such as the sadist's interest in torturing others. As well as the danger of arbitrariness – it requires no great imagination to foresee such a limiting rule being used to designate as inherently immoral interests in, for example, forming same-sex relationships - such a designation, of course, requires appeal to some extraneous ethical axiom, and for adherents to the Harm Principle, this may seem to bring them perilously close to legal moralism.

interpreted as including such matters as 'the child's need for a father', a 'need' that, were it not met, would be vastly unlikely to render a child's life WTN.

An approach which saw a small range of the most severe genetic disorders regarded both as suitable cases for prospective prohibition on implantation of such embryos under s.13(5), and for retrospective wrongful life actions raised on behalf of the children affected where negligence, malice or indifference saw the s.13(5) requirement ignored, would not provide a panacea to all the problems that bedevil this area, but it would lend a degree of coherence and consistency to an area that at present lacks both.

3.6 Conclusion

This chapter, then, contains several contentions, the most important of which can be summarised thus. First, being deselected/destroyed is harmful neither to the embryos themselves, nor the persons they might one day have become. In contrast, the potential future persons who will, or might, one day exist have (potential, future) interests that will one day be actualised, and these interests should be borne in mind in making 'genesis' decisions. However, as Parfit and others have shown, it is impossible to say that these future persons will be harmed by an act that brings about their existence, *provided* the lives into which they are born are not so wretched as to be worse than non-existence.

While this conclusion is recognised by most commentators in the field, many seek to circumvent the Non-Identity Problem/Principle by relying instead on some version of a utilitarian Non Person-Affecting principle, which creates duties to 'the class of potential future children who might exist' or, more commonly, to the world at large. The latter part of this chapter has been an attempt to show that such theories are themselves problematic, giving rise as they do to duties more onerous than their proponents would be likely to accept.

The next chapter of this thesis will consider some of the other candidates who might claim to be harmed, either by the very existence of a Genetic Supermarket, or by the specific decisions made by those who avail themselves of it. However, for the moment, it would appear that the overwhelming majority of choices that prospective parents would or could make about the genetic composition of their future children are harmful neither to the children themselves, nor, in any meaningful sense, to 'the world'. It is conceded

that this conclusion may feel, at some level, less than satisfying for anyone whose concern is with the quality of lives of existing and future persons; Glover has written that 'it is hard to accept that society should set no limits to the genetic choices parents can make for their children',[135] while Parfit himself seems far from satisfied by this conclusion.[136] It is submitted, though, that neither those two eminent philosophers, nor any other contributors to this debate, have offered an intelligible model which can account for the intuition that the Genetic Supermarket violates the Harm Principle.

I have therefore argued for a reading of s. 13(5) that is consistent with the Non-Identity Principle, i.e., a restrictive reading that would prevent the implantation only of those embryos likely to develop into children with WTN lives. Any embryos affected by lesser conditions should not be excluded from implantation; while the children they may become will be exposed to certain harms from which 'normal' children will be spared, their creation will not, predictably, constitute harms on balance, or at least not harms to *them*.

[135] Glover, *What Sort Of People Should There Be?*, op. cit., at p48.
[136] Parfit, *Reasons and* Persons, op. cit., at p443.

Chapter 4 Effects on third parties

In the preceding chapter, I sought to establish that the Genetic Supermarket ideal poses no credible risk of harm – conceived as a balance of disadvantage over advantage – to those potential children who might have been born but for the availability of this technology, or to those who actually are born as a result. The only credible exception would be in the presumably unlikely scenario where prospective parents utilised PGD to ensure the birth of a child afflicted with some genetic disorder so severe in its symptoms as to render the subjective quality of life of the child worse than non-existence.

In this chapter, I intend to consider the possibilities of risks of harm to other parties, less directly affected by the choices made by prospective parents, but who may nonetheless have interests that will be adversely affected by those choices. Typically, the 'negative externalities' considered here will arise (if at all) not from one or two isolated examples of PGD, but from the cumulative effect of many such choices; that is to say, the risk of such harms derives from the prospect of PGD becoming commonplace, and further, from those who use it making predictable, and similar, choices. Hans Reinders has expressed this concern in the following terms:

> side effects of individual decisions made by people using their reproductive freedom, though unintended, can collectively have very damaging effects in society. The question then is whether the proliferation of genetic tests should be restricted and whether such restriction is sufficiently justified on the grounds of the unintended but harmful side effects of large-scale use of such tests.[1]

Who, then, are these third parties who might be at risk of harm from the Genetic Supermarket?

[1] Hans S. Reinders, *The Future of the Disabled in Liberal Society: An Ethical Analysis*, Notre Dame, Indiana, University of Notre Dame Press, 2000, at p.86.

4.1 People with disabilities

4.1.1 Who are 'the disabled'?

The first category of potentially affected 'third party' interests belong to that section of society to whom we might refer as 'people with disabilities' or, somewhat more controversially, as 'the disabled'. For a variety of reasons, the choice of terminology in this area poses particular difficulties, and before attempting a consideration of the interests of such a group, it is important to clarify several points about the terms and concepts I will use. First, by deeming certain individuals as 'people with disabilities', I am in no way seeking to imply that their disability is their defining characteristic; although the question of whether (at least severe) disabilities can be identity-defining will be considered later in this chapter, most disabilities will be at most one of many attributes that combine to define an individual.

Secondly, I share with Susan Wendell and other writers the view that disability is both context- and task-specific. The first of these terms recognises that what constitutes a 'disability' in one context will often not do so in another; someone unable to undertake a particular activity – boarding a train, for example – in one society might well be able to do so in another society that made trains accessible to wheelchair users. The second term recognises that to speak of a 'disability' denotes a 'restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.'[2] Hence, an individual may well be 'disabled' in relation to one task (or range of tasks), such as climbing a flight of stairs, but be perfectly able to function in every other respect. Is it reasonable to designate such an individual as a 'disabled person'? For some commentators, the designation 'person with disability' better represents the fact that the disability may relate only to one, or a few, aspects of the person's life.[3]

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[2] The World Programme of Action concerning Disabled Persons, adopted by the United Nations General Assembly at its 37th regular session on 3 December 1982, by its resolution 37/52. 1/ Available at http://www.un.org/esa/socdev/enable/diswpa00.htm

[3] The Incapable Adults (Sc.) Bill was renamed the Adults with Incapacity (Sc.) Bill early in the drafting process to reflect precisely such concerns.

For the purposes of this discussion, I will use the terms 'disabled person' and 'people with disability' interchangeably. This is simply for reasons of linguistic convenience, and should not be taken to imply that I have disregarded the valid consideration that the people in question may well be 'disabled' for some purposes but not for many others.

Thirdly, it would be a serious mistake to assume that 'the disabled', or even the 'genetically disabled', are a homogenous group with a uniform set of circumstances, opinions or interests. Indeed, Susan Wendell has asked whether it is meaningful to speak of 'the disabled' as a single class at all:

> Is it not likely that living with disabilities is very different for people with different disabilities, and different for males and females, people of different ages, races, classes, occupations – perhaps so different that to lump them all together in a single category serves no useful purpose?[4]

Whether or not it is meaningful to group all disabled, or all genetically disabled, people into one class, even for the limited purposes of this thesis, is a question that lies beyond my present remit. Suffice to say that at least some commentators on the subject see some value in attempts to generalise about their experiences, or at least their treatment at the hands of a 'disability-phobic society.'[5] Indeed, having posed the question of the value in speaking of such a class, Wendell herself concludes that 'it is various aspects of their treatment by their societies that people with disabilities are most likely to have in common'.[6]

As will become apparent in this chapter, many of the concerns about how the Genetic Supermarket will impact upon people with disabilities derive from certain beliefs about how such people already are treated or perceived, and how their treatment or perception is likely to deteriorate as a consequence of widespread use of PGD. As such, and assuming there is any merit whatever in the views espoused by Fine and Asch, and

[4] Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability*, London, Routledge, 1996, at pp.30-31.
[5] Michelle Fine and Adrienne Asch, eds. *Women with Disabilities: Essays in Psychology, Culture and Politics*. Philadelphia, Temple University Press, 1988, at p.6.

Wendell, then there is validity in asking how PGD might impact on 'disabled people', even while acknowledging that there is certainly a degree of artificiality about this grouping.

In so doing, I recognise from the views of such people are likely to be as disparate and varied as any other cross-section of society, and that their views on PGD, neonatal tests and abortion are likely to vary as much as among society in general.[7] To see that this is true with regard to PGD, we need only contrast the almost diametrically opposed stances of the Genetic Interest Group (GIG), a 'national alliance of patient organisations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders'[8], and the Disabled Peoples' International (DPI) 'a network of national organizations or assemblies of disabled people, established to promote human rights of disabled people through full participation, equalization of opportunity and development.'[9]

In its 1999 publication *Genetic Testing, Screening and "Eugenics"*, GIG espoused an extremely positive view of PGD:

> In relation to pre-implantation diagnosis, the issues are more straightforward: if it is a matter of implanting three fertilised eggs out of a greater number, it seems to GIG sensible to implant those free of known genetic conditions. Most people would want to make that choice, and when it is possible to maximise the chances of a healthy child it appears to GIG to be perverse not to do so. There is no "slippery slope" because there are no difficult cases: it is good to avoid any and all disease, and that includes predisposition to disease in later life. Accordingly GIG opposes any and all attempts to

[6] Wendell, *The Rejected Body*, op. cit., at p.31.
[7] As 'disability activist' Marsha Saxton explicitly acknowledge; see 'Disability Rights and Selective Abortion', in Rickie Solinger, ed. *Abortion Wars: A Half Century of* Struggle, Berkley, University of California Press, 1998, pp.374-393, at p.380. See also Erik Parens and Adrienne Asch: the [disability rights] movement has no one position on prenatal diagnosis; from 'The Disability Rights Critique of Prenatal Testing: Reflections and Recommendations', in Parens and Asch, eds. *Prenatal Testing and Disability Rights*, Washington, D.C., Georgetown University Press, 2000, at p.4 (although, somewhat incongruously, Parens and Asch go on to speak in terms of 'the view of the disability community'; op. cit., at p.21.)
[8] http://www.gig.org.uk/
[9] http://www.dpi.org/en/start.htm

> restrict the range of medical conditions for which pre-implantation diagnosis can be performed.[10]

In marked contrast, the DPI's view of PGD and related practices is summed up in the following statement:

> We believe that no parent has the right to design and select their unborn child to be according to their own desires and no parent has the right to design their born child according to their own desires.[11]

Given such a plurality of opinions, how is it even possible to speak of possible harms to 'the disabled'? Based on these statements, it might seem likely that what might harm or offend the members of GIG will further the interests and ambitions of DPI, and vice versa.

In the discussion to follow, I divide the possible harms that a Genetic Supermarket approach might pose to disabled people into objective and subjective harms. The former category contains those harms which will occur irrespective of the views of the individuals in question. If, as in the argument I consider first, the effect of widespread use of PGD will be to reduce the actual resources available to disabled people, then that harm will eventuate regardless of whether those disabled people support or oppose, feel offended or comforted by, the technology in question. That being so, even disabled supporters of the GIG position could be harmed.

Those harms I refer to as subjective, in contrast, do in fact depend on the views and attitudes of the disabled people in question; in particular, they rely upon people with disabilities feeling hurt or offended or threatened or devalued by PGD, or by the

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[10] Genetic Interest Group, *Genetic Testing, Screening and "Eugenics"*, November 1999, available at http://www.wordsandpeople.com/gig/docs/gig_eugenics.pdf.

[11] DPI Bioethics resolutions from the 6th World Assembly Oct. 2002, Sapporo, Japan. Available at http://www.bioethicsanddisability.org/DPI.html. A further demonstration of this absence of consensus can be seen in the responses from 'disability groups' to the consultation process hosted jointly by the Human Genetics Commission and the HFEA. For example, in response to a question on replacing carrier embryos, three such groups replied that they 'should be replaced', two that they 'should not be replaced', and three that is should be the 'patients [sic] choice'; Outcome of the Public Consultation on Preimplantation Genetic Diagnosis, November 2001, Table 12, available at www.hgc.gov.uk/business_publications.htm)

particular uses to which it is put.[12] Thus, an evaluation of such possible harms requires some belief or other about how people with disabilities actually feel about, and how they are *likely* to feel about, PGD. Given that, as we have seen, there appears to be no consensus on this issue, it is of course difficult to evaluate the likelihood and gravity of this possible harm.

My consideration, therefore, will be of the contention that *some* people with disabilities will be at risk of subjective harms caused by a laissez faire approach to PGD. Since the purpose of this thesis is to consider the possibility of harm resulting from a largely unregulated Genetic Supermarket, my approach will not dwell on the perspective of those like the GIG, who are enthusiastic about PGD and therefore might be supposed not to be at serious risk of subjective harm. Rather, I will concentrate on the views of groups like DPI, and of writers on the subject of disability such as Marsha Saxton, Susan Wendell, Tom Shakespeare and Ruth Hubbard, who have expressed scepticism about, or outright hostility to, PGD or some applications thereof. In so doing, I am in no sense seeking to claim that their views are more representative of those of disabled persons in general than those of GIG or other pro-PGD groups or individuals. Rather, their objections will be examined simply because they are the ones that must be addressed if my hypothesis is to succeed. Insofar as I refer to the danger of harm to 'people with disabilities', this is again done for reasons of linguistic economy, and may be taken to denote those people with disabilities who hold certain views about the technology rather than *all* people with disabilities.

The fourth, and final, clarification about terminology relates to the very notion of 'disability'. There exists a wealth of literature on both sides of the debate over whether 'disability' is an objective phenomenon, caused by genetic or other physiological factors, or whether it is socially constructed;[13] for adherents to the former view, at least some

[12] A similar distinction – although not expressed in these terms – is drawn by Bonnie Steinbock; see 'Disability, Prenatal Testing, and Selective Abortion', in Parens and Asch, eds. *Prenatal Testing and Disability Rights*, op. cit., at pp.120-121..

[13] See John Harris, 'One principle and three fallacies of disability studies'. *Journal of Medical Ethics* 2001;27:383; Meg Stacey , 'The new genetics: a feminist view', in Theresa Marteau and Martin Richards, eds.

disabilities would constitute impairments to those affected in almost any imaginable society,[14] while social constructionists believe that 'disability' is merely (or largely) a product of a society organised to prioritise certain attributes more than certain others; as Parens and Asch have described this position, 'in a differently constructed social environment, what are now disabling traits would become "neutral" characteristics'.[15] (As the oft-cited example has it, in a society organised around the ability to hunt prey and avoid predators, poor eyesight could be a literally life-threatening disability, but in the contemporary western world, it is at most generally a minor impairment, easily correctable by spectacles.)

Fortunately, for the purposes of this discussion, I need adopt no firm position on this debate (although my own view is that there is almost certainly a degree of merit in the constructivist position, I can barely conceive of any possible society, however constructed, where a condition such as cystic fibrosis, which among its myriad disabling effects greatly reduces life expectancy, would not be disadvantageous). Rather, since the possible harms with which this section is concerned involve how 'society' responds, or is likely to respond to, people with disabilities in the world of the Genetic Supermarket, it is sufficient to note that, for whatever reason, certain traits are widely designated as 'disabilities', and those affected by them as 'disabled'. It is that very fact, rather than any particular belief about whether such 'disabilities' would exist independently of such attitudes, that gives rise to the concerns considered here.

4.1.2 'No World without Disabled People'[16]

Although they differ in other respects, all the objections considered in this section proceed on the basis that, however widespread the use of PGD eventually becomes, there

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The troubled helix, Cambridge University Press, 1996; Susan Wendell, *The Rejected Body*, op. cit., Chapter 2; Philip Kitcher, *The Lives To Come*, Allen Lane The Penguin Press, 1996, at p.208; William Roth, 'Handicap as a Social Construct', *Society*, March/April 1983, 56-61.

[14] See Harris, 'One principle and three fallacies of disability studies', loc. cit., and Feinberg, 'The child's right to an open future', op. cit.

[15] Erik Parens and Adrienne Asch, 'The Disability Rights Critique of Prenatal Testing: Reflections and Recommendations', in Parens and Asch, eds. *Prenatal Testing and Disability Rights*, Washington, D.C., Georgetown University Press, 2000, at p.23.

[16] Reinders, *The Future of the Disabled in Liberal Society*, op. cit., at p.81.

will continue to be *some* disabled people in our society. Otherwise, these objections would be meaningless; what would it mean to worsen the situation of disabled people in a society in which there are no disabled people?

Obviously, PGD will not eliminate the possibility of disability through accident (including injuries sustained at birth), but it is also overwhelmingly likely that even as PGD becomes more accurate, it will remain imperfect; some genetic disabilities will 'slip through the net'. Furthermore, it is also highly improbable that a situation will arise where every prospective parent will agree to utilise PGD. The Public Consultation carried out jointly by the HFEA and the Human Genetics Commission, the results of which were published in November 2001, revealed that 30% of individual respondents were opposed to PGD in general,[17] while 8 of the 20 respondents 'who indicated some experience of disability, including carers, families as well as disabled individuals themselves'[18] voiced general opposition.

Even in Andrew Niccol's dystopian *Gattaca*, which imagines a society wherein the use of PGD is all but compulsory, some non-conformist parents elect to entrust their children's genetic composition to chance, having what are regarded as 'faith babies'. For that substantial minority of the UK population that regards human life as acquiring full moral status at conception, the use of IVF deliberately to create more embryos than will ever become children is itself ethically problematic, irrespective of how the decision is made as to which of them to implant. Such people, it may be presumed, will never utilise PGD technology. Furthermore, some of the very people this section explores – those disabled people who object to the use of PGD to 'screen out people like them' – may be presumed unlikely to use this technology themselves, preferring in most cases to entrust the genetic endowment of their own children to chance, or occasionally taking steps such as McCullough and Duchesneau to maximise the chance of having a child that shares their own 'disabling' genetic traits.

[17] Joint Working Group of the HFEA and Human Genetics Commission, *Outcome of the Public Consultation on Preimplantation Genetic Diagnosis*, November 2001, at p.12.
[18] Ibid, at p.11.

It is also possible that a percentage of 'disabled' people is an inevitability in any society, if the 'disabled' are defined relative to the majority of the population. There will, for example, always be a 1% of the population with the poorest eyesight or weakest limbs, regardless of whether – in some future society – that 1% is merely average by the standards of today. On this relativist conception, disability may be not only an inevitability, but a constant.

4.2 Objective harms

4.2.1 Weakening the position of disabled persons in society

Perhaps the most concrete species of possible harm relates to the actual impact of a Genetic Supermarket upon the status and prospects of the disabled within society. This involves an objective determination – whatever they might think, their position actually *is* weakened - and might take one of a number of forms. The most straightforward suggestion is that a reduction in the numbers (either absolutely, or as a proportion of the population) of persons affected by particular conditions will reduce the perceived importance of finding cures, treatments or ways to improve the lives of those remaining affected persons. As regular commentator on disability issues Tom Shakespeare says:

> reducing the number of impaired foetuses born will possibly lessen the likelihood of effective therapy for affected people: as a condition becomes rarer, the impetus to discover a cure or treatment diminishes. This reinforces my wider feeling, that genetic screening will never be total, which means that the proportion of congenital impairment may be reduced, but not eliminated, which means that disabled people will be further isolated, face increasing prejudice, and the pressure to make society accessible to all will be reduced.[19]

[19] Tom Shakespeare. 'Back to the future? New genetics and disabled people'. *Critical Social* Policy (1995); 15 (2/3): 22-35, at p.31. Susan Wendell has expressed a similar concern: 'It might weaken efforts to increase accessibility and opportunities for people with disabilities, because it appears to reduce the social problems of people with disabilities by reducing the number of people with disabilities. ... If so, we have to ask what will be the social fate of people who already have disabilities and those who, in the future, will become disabled by accident or disease.' *The Rejected Body: Feminist Philosophical Reflections on Disability*, London, Routledge, 1996, at p.154.

This is what Allen Buchanan has deemed the 'loss of support' objection.[20]

Shakespeare offers no empirical evidence in support of his contention that such a reduction would lead to a diminution in support, but his thesis may not be entirely implausible. It is at least worthy of some further examination within an analysis of third party interests. Is it, we might reasonably wonder, plausible that millions of pounds of research funding would be given over to the investigation of potential treatments for conditions that affect only a handful of people? Is it likely that buildings and buses would have been rendered 'wheelchair accessible' if there were but a few dozen wheelchair users?

It is also, however, possible that in certain practical respects, the position of some existing disabled people (or those who will nonetheless come to exist) may be improved by a reduction in the number of similarly affected people. This might apply in cases where the nature of their disability or illness was such that it required scarce or resource-heavy support, assistance or treatment. A condition which may require access to kidney dialysis, for example, or to organ transplantation (such as cystic fibrosis) will often see affected parties forced to 'compete' with other candidates for these treatments or scarce resources. Their chances of gaining access to those scarce resources, we might reasonably expect, will improve in inverse proportion to the number of similarly affected individuals who are also vying for those resources.[21]

Even, though, were we to accept that there is merit in Shakespeare's claim that the position of existing affected people will be weakened by preventing the creation of more

[20] Allen Buchanan, 'Choosing who will be disabled: genetic intervention and the morality of inclusion', *Social Philosophy & Policy* (1996); 13(1): 18-46, at p.21. Laura M. Purdy also writes of the notion that there is a possibility 'that if we attempt to avoid the birth of children with disease or disability, we will harm those who already exist. At the most practical level, some believe that acting so as to avoid such births will lead us to reduce the social resources now allocated to the disabled.' From 'Loving Future People', in *Reproduction, Ethics and the law: Feminist perspectives,* ed. Joan C. Callahan, Indiana University Press, 1995, p.312. See also Philip Kitcher, *The Lives To Come*, Allen Lane, The Penguin Press, 1996, at p.200.

[21] Philip Kitcher offers just such an example, of beta thalassemia in Cyprus: 'As the incidence of thalassemia has diminished, help for the afflicted has increased: Because there is now less demand for blood transfusions and

similarly affected people (and it is quite possible that their position could be weakened in some respects, while being strengthened in others), this does not invariably lead us to any particular conclusion as to how this 'harm' should be redressed. In particular, it does not lead immediately to the conclusion that the interest of existing affected people in having their numbers maintained should give rise to an obligation incumbent on prospective parents to contribute to those numbers.

The difficulty of such an obligation might be illustrated by analogy with a slightly different example of disability. The teratogenic effects of the drug Thalidomide resulted in the birth of thousands of children with phocomelia (incompletely developed limbs).[22] Despite certain legal obstacles to a claim in either delict/tort or contract law, the drug's victims managed to secure an *ex gratia* payment from the drug's manufacturers. It is, perhaps, not overly contentious to speculate that this was achieved largely as a result of lobbying by and on behalf of those children, and of sympathetic depictions of their plight in the media, both of which would have been considerably diminished had there been far fewer 'Thalidomide children' in the world. Quite simply, their case was stronger because there were ten thousand (or more) of them, rather than fifty or a dozen.

Supposing, however, that the teratogenic properties of Thalidomide had been discovered and made widely known in 1955, one year after it was marketed, rather than 1961? Had the drug been withdrawn at that point, many thousands of children could have been spared the effects of the drugs, but it also seems inevitable – following Shakespeare's logic - that the position of those already affected, and of their parents, would have been that much politically weaker. Does it follow that Thalidomide should have continued to have been prescribed, that information pertaining to its side-effects should have been

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other treatments, the lives of thalassemia sufferers are now better than they were.'Philip Kitcher, *The Lives To Come: The Genetic Revolution and Human Possibilities*, London, Allen Lane The Penguin Press 1996, at p.85.

[22] Estimates of the precise number of children affected worldwide vary, but it is widely accepted that the number was in excess of 10,000; Knight P. *Suffer the Children: The story of thalidomide*. Andre Deutsch, 1979; Nippert I, Edler B, Schmidt-Herterich C. '40 years later: the health related quality of life of women affected by thalidomide.' *Community Genetics* (2002);5(4):209-16.)

suppressed? Would the interest of existing Thalidomide families in having their movement grow stronger have been sufficiently compelling to justify the denial of the freedom of pregnant women to make an informed decision as to whether to carry on taking the drug?

Of course, it may be pointed out, the analogy between Thalidomide and genetic screening is in certain respects imperfect. Most significantly, the Non-Identity Principle discussed in Chapter 2, and on which much of my thesis depends, may not apply in the context of Thalidomide. The Thalidomide children, after all, are not like Parfit's hypothetical future child of the 14-year old girl, in that for them, existence free from disability *was* an option; quite simply, had their mothers not taken the drug, they would in all probability have been born with normally developed limbs.

The significance of this purported disanalogy will be considered in due course, but for present purposes, it is sufficient to note that whatever its importance in other respects, it does not answer Shakespeare's concern. For the argument as he expressed it does not depend on any particular facts or beliefs about the identities of the disabled children who are 'screened out of existence'; rather, it is the mere fact that fewer disabled children are born that is purported to harm the interests of existing disabled people, and this harm will eventuate regardless of whether they are 'replaced' with 'the same children *sans* disablilities' or 'different children altogether' (or indeed, with no children at all). The salient fact is that the sheer numbers of disabled people will be reduced, resulting in the presumed diminution of their political power or attention to their particular needs and interests.

What we might wish to say here is that, in both cases, there exists a tension between parental choice and the interests of existing handicapped people, but it is only in the Thalidomide (and therefore not in the PGD) case that the scales are decisively tipped by the prospect of harm to the resulting child. I aim to demonstrate later in this section that the reality is not so straightforward, but for present purposes, it is informative to consider

the implications of such a position. It involves taking the view that the only reason why Thalidomide should have been withdrawn, or indeed why pregnant women should have been presented with an informed choice as to whether or not to use it, is because of the harm it would inflict on future children. Their own interest in avoiding the birth of a disabled child (in many cases, children who died within their first year of life), coupled with their interest in making that choice for themselves, is outweighed by the distant and disparate interests of existing Thalidomide 'victims' in having their 'bargaining position' strengthened. It is not my intention to dwell further on the merits of this contention; different views may exist as to where the respective weights of these interests lie. Suffice to say that if this conclusion is deemed unacceptable, then it follows that Shakespeare's contention, while it may have more than a hint of truth, does not present a persuasive reason for rejecting the Genetic Supermarket.[23]

4.2.2 Creating a class of 'undeserving disabled'

A slightly different version of the same concern has been expressed by Hans S. Reinders, in his book *The Future of the Disabled in Liberal Society*. For Reinders,

it is not a question of the decreased size of the disabled population that will constitute a problem for remaining disabled people, but the perception that their existence was a matter of parental choice rather than biological chance:

> Assuming that disabled people will always be among us, that the proliferation of genetic testing will strengthen the perception that the prevention of disability is a matter of responsible reproductive behavior, and that society is therefore entitled to hold people personally responsible for having a disabled child, it is not unlikely that political support for the provision of their special needs will erode. If this development takes place, their access to social services, welfare, education, and the labor market will be in danger ... At any rate, it will be much more in danger than when the general conviction is that disabled people should enjoy these social goods because of the special needs that they have without any fault of their own.[24]

[23] A similar response to the 'loss of support' objection is advanced by Buchanan; 'Choosing who will be disabled', loc. cit., at p.23.

[24] Hans S. Reinders *The Future of the Disabled in Liberal Society: An Ethical Analysis*, Notre Dame, Indiana, University of Notre Dame Press, 2000, at pp.14-15.

Specifically, Reinders talks of the danger that 'The general attitude will be that people with special needs should be legitimately entitled to social benefits but that it is fair to withdraw such benefits as soon as these special needs are no longer a matter of misfortune but can be attributed to personal responsibility.'[25]

Is it in fact likely that such an attitude will be brought about by the presence of the Genetic Supermarket? Although the scope of this thesis does not extend to sociological investigation, a couple of reasons exist that may cast some doubt on Reinders' hypothesis. The first derives from the reasons why we do, or should, provide benefits or assistance for disabled people in the first place, while the second relates to what precisely it is possible for prospective parents to avoid.

The answer to why we think it morally important to devote some resources to those affected by disabilities derives, at least in part, from a notion of justice. As Allen Buchanan says:

> there is an obligation to devote some social resources to preventing or correcting undeserved differences in initial social or natural assets that result in some persons' [sic] suffering significant limitations on their opportunities – limitations so serious as to interfere with their having reasonable prospects for a decent life.[26]

This notion of justice, then, regards it as unfair that anyone should be abandoned to a poorer or more restricted life because of factors that were not the product of their choice or control, be they social, environmental, or genetic. Is this obligation weakened when the disabilities or disadvantages are the product of their own choice? Some commentators certainly think so,[27] though the preponderance of academic bioethical

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[25] Reinders *The Future of the Disabled in Liberal Society*, op. cit., at pp.79.

[26] Allen Buchanan, 'Choosing who will be disabled: genetic intervention and the morality of inclusion', *Social Philosophy & Policy* (1996); 13(1): 18-46, at p25. See also Jonathan Wolff: 'one is responsible for those results of one's freely chosen actions or decisions, but should receive compensation (or pay tax) for the results of bad (good) luck.' 'Tin Genes and Compensation', in Justine Burley, ed. *The Genetic Revolution and Human Rights*, Oxford, Oxford University Press, 1999, at p.133.

[27] See, for example, Moss, A.H., Siegler, M. 'Should Alcoholics Compete Equally for Liver Transplantation?' *Journal of the American Medical Association* (1991); 265(10): 1295-1298; 'Should Smokers Be Offered Coronary Bypass Surgery?', debate in (1993) 306 *BMJ* 1047.

opinion seems to favour the view that, at least regarding the provision of medical treatment, such value judgements are inappropriate.[28]

Perhaps more damaging to the 'argument from responsibility' is the fact that, even were we to adopt a 'tough' stance on self-induced disadvantage or disability, the parties whose choices have 'caused' the disability (or more accurately, allowed it to come into existence) are different people entirely from those who will be affected by it, and who may require assistance in the form of state benefits, medical assistance or whatever else. Even if society came to view the decision to have a 'faith baby' as reckless and irresponsible, it would be unfair and irrational to visit the adverse consequences of such recklessness upon the entirely innocent children themselves. Is it possible that public opinion will follow this unfair and irrational path, will come to resent this 'tax for other people's bad genes'[29], and exert pressure upon their political representatives to withhold or reduce the benefits payable to such children? Perhaps. But the blame for any such attitudes would surely lie with a societal mindset that habitually blamed children for their parents' bad choices, rather than the fact that such choices existed.[30]

The second reason why the 'argument from responsibility' might not constitute a compelling argument in this context derives from the fact that, insofar as it is intelligible to hold individuals responsible for the consequences of their own actions or inactions, it

[28] Raanan Gillon's position, for example, is 'that patients should be given treatment in relation to their medical need, and that scarce resources should not be prioritised on the basis of a patient's blameworthiness.' 'On giving preference to prior volunteers when allocating organs for transplantation.' *Journal of Medical Ethics* (1995); 21: 195-196, at p196. See also Cohen, C., Benjamin, M. 'Alcoholics and Liver Transplantation' *Journal of the American Medical Association* (1991); 265(10): 1299-1301. One possible response to the view that individuals should be left with the consequences of their own choices would ask whether, and to what extent, those 'choices' were themselves the product of factors outwith their control, such as a genetic predisposition to addiction or poor education during childhood.

[29] Reinders, *The Future of the Disabled in Liberal Society*, op. cit., at p.90.

[30] Libertarian commentator Hillel Steiner has argued that the genetic revolution 'shifts responsibility from nature to particular persons', specifically to the parents of genetically disadvantaged children insofar as the had it within their power to prevent such disadvantages; thus, in such cases, compensation to the child should be from the negligent parents and not the state. However, even leaving aside the question of whether the parents may possess the means adequately to redress this disadvantage, Steiner concedes that – in view of the Non-Identity Principle – this transfer of responsibility would be appropriate only in cases where gene therapy (which he supposes to be non identity-altering) was available, but not where PGD was declined. 'Silver Spoons and Golden Genes: Talent Differentials and Distributive Justice', in Justine Burley, ed. *The Genetic Revolution and Human Rights*, Oxford, Oxford University Press, 1999, pp. 146-148.

is only logical to do so when there were other alternatives available to them. Hence, it would be intelligible to hold parents responsible for the birth of their 'faith babies' only if the option of screening embryos had been open to them, and they had declined it.

How likely is it that PGD will ever be a practically accessible option for all? On Nozick's approach, certainly, prospective parents will be free from state interference or restriction with such choices, and in that sense PGD will indeed be an option. But, as has been often noted, freedom *from* interference with a choice is not synonymous with freedom *to* act upon that choice. The other side of Nozick's laissez faire approach would, presumably, deny that it is the responsibility of the state, or of other people, to provide the means to act upon that choice – what I refer to later as the 'hard' version of the Genetic Supermarket hypothesis. While the prospect of a Genetic Supermarket in which only 'the rich' (however defined) can shop presents its own problems (see Section 3 of this chapter), it does perhaps provide one possible response to the argument from responsibility: it is illogical and unfair to hold a parent responsible for not utilising PGD when, for reasons of inadequate resources, they could not afford to do so. And, given that this objection is directed at those who will, or whose disabled children will, be reliant upon state benefits, it is perhaps not implausible to imagine that they will not constitute the wealthiest section of society.[31]

Again, it is not my contention that the general public *would* subscribe to such a view; it is always possible that those for whom PGD lies beyond their means would be subjected to a sort of 'double jeopardy', blamed both for their poverty and for the consequences of that poverty. However, in an ethical evaluation such as this, it is perhaps worthy of note that, at least according to the common conception of justice considered later in this chapter, the attribution of responsibility *should* take note of what was, in reality, possible for the parents of disabled children. If it is reasonable to penalise children for the bad

[31] Of course, I recognise that more severely disabled children may require full-time care or assistance, or specialist treatment, which may lie beyond the means of even moderately wealthy families, families for whom PGD would have been affordable. Nonetheless, insofar as this objection derives its emotional force from its seeming concern with the least wealthy, it is worthy of note that they should, by rights, be excluded from any such attribution of 'blame'.

choices of their parents – and I maintain that it is not – then it is at least surely unreasonable to penalise them when any such choices were, in fact, illusory.

4.2.3 Subjective harms: causing disabled people to *feel* devalued

If the concern is about how existing disabled persons will feel in the face of this technology, then the measurable impact, in terms of reduction in political strength or public sympathy, may be less relevant than the personal, subjective testimony of actual disabled people. In this regard, there appears to exist in the literature ample evidence of distress and offence in the face of the perceived message that, as one commentator put it, 'some of us are "too flawed" in our very DNA to exist; we are unworthy of being born.'[32] In order to evaluate this concern, it is necessary to consider who, precisely, it is that is thought to be sending this message. For the purposes of this discussion, I have considered separately the suggestions that (a) it emanates from parents, and (b) it emanates from 'society'.

4.2.3 By their parents

Disability activist Marsha Saxton has contributed some obviously deeply personal contributions to several collections on reproductive technologies. In one such chapter, she recalls her own first exposure to the choices posed by the existence of prenatal testing:

> I remembered the spina bifida newsletter when I first read about the AFP [alpha-feto protein] test available to detect spina bifida and other neural tube defects. I remember having mixed feelings. Could I choose to abort a baby with my own disability, end the life of someone somehow an even closer kin to me than my own child? But then could I choose to continue the life of someone possibly destined to endure some of the same treatments I had experienced? Another thought emerged: if this test had been available to my mother I might never have been born.[33]

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[32] Marsha Saxton, 'Disability Rights and Selective Abortion', in Rickie Solinger, ed. *Abortion Wars: A Half Century of* Struggle, Berkley, University of California Press, 1998, pp.374-393, at p.391.

[33] Marsha Saxton, "Born and unborn: the implications of reproductive technologies for people with disabilities" from *Test-Tube Women: What future for motherhood?*, ed. Rita Arditti, et al (Pandora Press, 1984), at p.301.

The last sentence raises two rather different concerns. One, that in 'screening out' those embryos deemed to be 'disabled', we will be depriving society of valuable contributors (such as, undeniably, Saxton herself), will be addressed later in this chapter. But Saxton's reference to her mother might suggest the possibility of a different sort of psychological anguish, arising from a sort of counterfactual parental rejection. If my mother had had the option of this test, Saxton seems to be saying, she would have rejected me.

A similar sense of hurt has been expressed by Deborah Kent:, who has written of her disappointment in the face of the reactions from her parents and husband at the prospect of giving birth to a child that shared her genetic blindness:

> I will always believe that blindness is a neutral trait, neither to be prized nor shunned. Very few people, including those dearest to me, share that conviction. My husband, my parents, and so many others who are central to my life cannot fully relinquish their negative assumptions. I feel that I have failed when I run into jarring reminders that I have not changed their perspective. In those crushing moments I fear that I am not truly accepted after all.[34]

It is not difficult to understand how such a belief – that their very existence was a result only of their parents' lack of choice, and that given that choice they would have been rejected - could be painful to anyone who values their relationship with, and the esteem in which they are held by, their parents. Does this, then, provide a concrete example of harm caused by the Genetic Supermarket (expanded, as in Saxton's scenario, to include those prenatal tests that have been available for many years)?

There are, I believe, at least three possible responses to the 'rejection' concern that, while not necessarily allaying all of the concern felt by people like Saxton and Kent, at least give pause with regard to the coherence of those concerns, or their direct relevance to the Genetic Supermarket. First, it might be pointed out that, in one way or another, most of us owe our existence to the lack of choice open to our ancestors; had sex education, effective contraception and perhaps the notion of female reproductive

autonomy been available to the generations that preceded us, it is more than likely that, somewhere in our genetic lineage, an ancestor would have elected not to have as many children, to have children at precisely that time, or indeed to have children at all, with the result that we would never have come to exist. Presumably, few of us would consider that this provides a reason for denying those choices to women today.

Should this realisation prove comforting to those who, like Saxton, are concerned about what her mother might have done had prenatal testing been available to her? Perhaps she might retort that, while my ancestors may indeed have elected not to have a child, or another child, or a child at that precise time, they would not have been rejecting *this particular child*, and certainly not on the grounds of certain characteristics that this child possessed. This is the position adopted by Theresa Degener -

> Of course, the non-selective abortion of a pregnancy that was undesired from the start also views the fetus as a burden, but this evaluation is not based on an individual characteristic of the potential child, but on aspects that are unrelated to the fetus, such as the woman's living conditions and the way she wants to lead her life. The special character of selective abortion lies in wanting to opt for a so-called norm(al) child and reject a disabled child.[35]

- and is what Adrienne Asch has deemed the 'any-particular distinction': while 'most abortions reflect a decision not to bring any fetus to term at this time ... selective abortions involve a decision not to bring this particular fetus to term because of its traits'.[36]

Are Degener and Asch right to assume, though, that a decision to 'screen out' a disabled embryo is unique in its implicit negative connotations about certain existing children? Are decisions to avoid the birth of a fifth or sixth child, a child born into conditions of poverty, or, to return to Parfit's example, a child born to a girl too young to look after it properly, devoid of any such connotations? In exactly the same way as, for Saxton, the

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[34] Deborah Kent, 'Somewhere a Mockingbird', in Parens and Asch, eds. *Prenatal Testing and Disability Rights*, op. cit., at p.62.
[35] Theresa Degener, 'Female self-determination between feminist claims and "voluntary" eugenics, between "rights" and ethics', *Issues in Reproductive and Genetic Engineering* (1990), 3(2), 87-99, at pp.92-93.
[36] Erik Parens and Adrienne Asch, 'The Disability Rights Critique of Prenatal Testing: Reflections and Recommendations', in Parens and Asch, eds. *Prenatal Testing and Disability Rights*, Washington, D.C., Georgetown University Press, 2000, at p.15.

decision to avoid the birth of disabled children constitutes a rejection of, and affront to, existing disabled people, do not these other decisions tacitly imply negative evaluations of children born into large families, into poverty or to young teenaged mothers? Indeed, precisely this point is made by James Lindemann Nelson:

> even granting, for sake of argument, that abortion to prevent disability sends a disrespectful message to disabled people, why would abortion on the basis of family size, or poverty, or for any other reason, not send similarly disparaging messages to children of large families, or the poor, or to those who share with the fetus whatever properties that were the basis of the abortion decision?[37]

Those who agree with Saxton, then, must demonstrate why a decision to avoid the birth of a disabled child sends an emotionally harmful message to existing disabled people while a decision to avoid the birth of a child into difficult social or economic – as opposed to genetic – circumstances does not send an analogous message to poor families, large families or families with very young mothers.

The second objection takes issue with the assumption that, in opting not to give birth to a disabled child, prospective parents are devaluing life with disability. Reinders advances the view that it is possible for prospective parents to screen out (or abort) an embryo (or foetus) with a particular condition without making a discriminatory judgement about people with that condition:

> If a couple after having had a prenatal test decides to abort the fetus because it is affected by Down [sic] syndrome, they can justify this decision by referring to what they think they are capable of in raising a family.[38]

As Buchanan notes, there may be a number of reasons why parents wish their children to possess certain traits that do not necessarily presuppose a discriminatory attitude against those who lack them: 'One may wish to avoid serious strains on one's marriage, on one's ability to fulfil responsibilities to one's other children, or on scarce social resources'.[39]

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[37] James Lindemann Nelson, 'Prenatal Diagnosis, Personal Identity, and Disability', *Kennedy Institute of Ethics Journal* 10.3 (2000) 213-228, at p.216

[38] Reinders, *The Future of the Disabled in Liberal Society*, op. cit., at p.93.

[39] Buchanan, 'Choosing who will be disabled', loc. cit., at p.32. A similar point is made by Bonnie Steinbock in her chapter 'Disability, Prenatal Testing, and Selective Abortion', in Parens and Asch, eds. *Prenatal Testing and Disability Rights*, op. cit., at p.119.

Furthermore, prospective parents may, for example, simply wish their children to share certain of their own characteristics, perhaps in pursuit of some kind of 'genetic immortality', perhaps because they simply feel that they will be more easily and happily assimilated within the existing familial environment if they do.[40]

Indeed, we have considered an example of just such a wish already in this thesis, when we looked at the attempts of Candy McCullough and Sharon Duchesneau to ensure their child was 'deaf like them'. Such attempts did not presuppose that the life of the hearing was in any sense inferior to that of the deaf (although it is possible that McCullough and Duchesneau did harbour such attitudes), merely that their lives are sufficiently different as to constitute a barrier to sharing certain of the same experiences as their parents.

Whatever the precise reason, there may be a number of possible explanations for parents preferring a child with certain qualities, none of which involve a generalised assumption of inferiority of those without those qualities. In the case of those qualities the absence of which are conventionally regarded as 'disabilities', the reason may simply be a recognition, or belief, that they themselves lack the financial, physical, social or emotional resources necessary to raise such a child; they may be recognising their own limitations, rather than deeming the child as 'sub-standard' or 'unfit to live.'[41] As Theresa Degener notes,

> there is as little harm in wanting to have a nondisabled child as there is in wanting to have a disabled child. ... It is only when this wish for a nondisabled child is declared universal and it becomes mandatory to resort to supposedly infallible technological means to ensure that it is fulfilled that it becomes a danger and a duty.[42]

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[40] A point of view expressed by Mary Ann Baily, who candidly admits her own unease at the prospect of any future child she bore being co-opted into a 'disability culture' from which she herself was excluded; 'Why I Had Amniocentisis', in Parens and Asch, eds. *Prenatal Testing and Disability Rights*, op. cit., at pp.68-69.

[41] See James Lindemann Nelson, 'Prenatal Diagnosis, Personal Identity, and Disability', loc. cit., at pp.215-216. See also Parens and Asch. 'The Disability Rights Critique of Prenatal Testing', op. cit., at p.15, where they note that 'Parents of one child with a disability may believe that they don't have the emotional or financial resources for another.'

[42] Degener, 'Female self-determination... ', loc. cit., at p.95.

The third possible response to Saxton's objection is that the (for her) distressing possibility that her mother would have opted for an abortion, and any emotional anguish she suffers as a result of acknowledging this possibility, is not dependent upon any particular state of affairs obtaining in the present time. Whether or not the choice of PGD is made available to today's potential parents, she will nonetheless have to confront the evidently uncomfortable possibility that, had she had a choice, her mother might have opted for an abortion. At most, denying the option of PGD to another generation of potential parents will simply give rise to another generation like Saxton who will wonder, with varying degrees of discomfort, what their parents might have done had they had the choice.

4.2.4 By 'society'

The view that 'society' is sending a negative message to disabled people that they are not wanted is well summarised by Susan Wendell. In *The Rejected Body*, she addresses the issue of prenatal testing, followed by abortion of any foetuses found to be disabled:

> the widespread use of selective abortion to reduce the number of people born with disabilities ... sends a message to children and adults with disabilities, especially people who have genetic or prenatal disabilities, that "we do not want any more like you".[43]

In a similar vein, Hans S. Reinders observes that

> it appears as though our society is simultaneously sending two messages to the disabled and their families. The first message says, "Since you're here, we're going to care for you as best we can," but the second says, "But everyone would be better off if you were not here at all"'[44]

while Bill Albert of Disabled Peoples' International has argued that 'No one should have to live that life in a society which values them so little it makes a social and medical virtue out of eliminating people who might be like them.'[45]

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[43] Wendell, *The Rejected Body*, op. cit., at p.153.

[44] Reinders, *The Future of the Disabled in Liberal Society*, op. cit., at p.4.

[45] Bill Albert, 'The New Genetics and Disability Rights', Presentation to EU Conference 'Human Genetic Testing, What Implications', Brussels, May 6, 2004, available at http://www.dpi.org/en/resources/topics/bioethics/05-10-04_balbert.htm. See also 'Disabled People Speak on the New Genetics', DPI Europe Position Statement on Bioethics and Human Rights, available at http://www.dpieurope.org/htm/bioethics/dpsngfullreport.htm. See also Laura M. Purdy: 'At a more theoretical level, the judgement that life is better without such problems is taken as an insult to those now facing them.' From

Is it necessarily true, though, that 'screening out' of certain genetic conditions implies a devaluing of *people* with those conditions? Attempts to eliminate smallpox, or leprosy, or rickets, were not taken to imply that those affected by such conditions were devalued, and it is unlikely that they regarded attempts to eliminate such diseases as offensive. As Reinders says,

> We fight cancer; we do not fight people with cancer. If research to eliminate cancer does not imply an attitude that supports discrimination against persons who suffer from this disease, why should clinical genetics be different?[46]

Reinders calls this the Distinction between the Person and the Condition (DPC) argument, according to which 'The charge of negative evaluation is completely unjustified, therefore. It is based on the false identification of persons with their conditions.'[47]

Reinders goes on to acknowledge, though, the obvious rebuttal to the DPC that

> with very few exceptions, the genetic diseases that are currently known can be "treated" only by eliminating the fetuses that are affected. In actual practice the distinction between persons and their conditions remains inconsequential, therefore.[48]

Whereas it is possible to detroy cancer cells while leaving alive those persons who were affected by them, the same cannot be said of screening out genetic disorders, where the only means by which the disorder can be avoided necessarily involves 'avoiding' the person as well. In other words, it is not simply the disorder that is being rejected, but the whole package of person-plus-disorder. This, surely, is distinct from attempts to eliminate somatic (or even treatable genetic) disorders.

As suggested at the end of Chapter 2, however, the conclusion that identity is synonymous with genetic identity is by no means uncontentious. Is there not at least a

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'Loving Future People', in Joan C. Callahan, ed. *Reproduction, Ethics and the law: Feminist perspectives.* Indiana University Press, 1995, at p.312; Meg Stacey, 'The new genetics: a feminist view', in *The troubled helix*, eds. Theresa Marteau and Martin Richards, Cambridge University Press, 1996, at p.343.

[46] Reinders, *The Future of the Disabled in Liberal Society*, op. cit., at p.55.

[47] Id.

[48] Ibid, at p.56.

plausible case for believing that other conditions, particularly those which act upon the brain, might also be thought to be 'identity defining'? This has certainly been the perspective of a number of bioethicists in relation to conditions such as Alzheimer's Disease.[49] Indeed, at least one author would argue that this expressivist objection could be applied to practically any attempt to 'cure' a disabling condition, genetic or otherwise:

> If abortion on the basis of prenatal diagnosis sends a "we don't want your kind here" message, why would therapeutic interventions not do so as well - and the more successful the therapies are, the more effective the message? If abortion to avoid parenting a child with disabling conditions involves making a decision based on a single trait, would not efforts to cure or prevent disability also involve value assessments based on a single trait? If testing and abortion militate against social acceptance of disabilities as examples of human variation, why would testing and treating not do so as well?[50]

For present purposes, it is not necessary to consider precisely which disabling conditions might be properly be regarded as 'identity defining', and therefore to come within the ambit of the expressivist objection. It is sufficient that we consider seriously the possibility that some – those which impact most severely upon cognitive functioning, awareness of self, memories, aspirations and wants – can be said to be so. A treatment for Alzheimer's Disease would result in a society where 'different' people existed than one where Alzheimer's is not cured. If this is true, then attempts to eliminate Alzheimer's Disease may well fall foul of the expressivist objection, carrying an implicit statement of devaluing or rejecting those affected by the disease. Can we therefore

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[49] An intriguing ethical discussion of Alzheimer's disease and continuity of identity has centred around the issue of advance directives. Dan Brock has written of the situation where 'the cognitive changes in the patient are so profound as to call into question whether personal identity is maintained between the earlier and later selves'. See, in particular, the notable contribution of Rebecca Dresser to the literature on this point: 'Advance directives, self-determination, and personal identity', in Hacker, C., Moseley, R., Vawter, D., eds. *Advance Directives in Medicine*, New York, Praeger Publishers, 1989; 'The Incompetent Patient on the Slippery Slope'. *Hastings Center Report* July-August 1994, 6-12 (with P.J. Whitehouse); see also Mark Kuczewski 'Whose Will Is It, Anyway? A Discussion of Advance Directives, Personal Identity, and Consensus in Medical Ethics.' *Bioethics* (1994) 8(1):27-48; Helga Kuhse 'Some Reflections on the Problem of Advance Directives, Personhood and Personal Identity', *Kennedy Institute of Ethics Journal* (1999) 9(4): 347-364.

[50] James Lindemann Nelson, 'Prenatal Diagnosis, Personal Identity, and Disability', *Kennedy Institute of Ethics Journal* 10.3 (2000) 213-228, at p.219

conclude that society devalues or disrespects or rejects those with late-stage Alzheimer's?[51]

It might be thought, then, that the analogy between genetic screening and attempts to reverse the effects of plausibly identity-defining conditions such as Alzheimer's disease is stronger than some adherents to the expressivist objection seem to recognise. If this is so, then if we conclude that genetic screening sends a negative message to existing disabled people, then this must be equally true of existing mentally impaired individuals when we pursue 'cures' for their conditions; 'cures' which, I suggest, would replace them with different persons just as surely as PGD. If, on the other hand, we do not regard these efforts as implicitly devaluing existing mentally impaired individuals, then neither should we regard PGD as implicitly devaluing those affected by genetic disorders.

On this view, then, 'screening out' certain conditions does not, or need not, send out a negative statement to anyone, by anyone, or in any event at least no more so than an attempt to cure a disease such as Alzheimer's. Even if this view is rejected, however, there may be thought to exist a number of other reasons to doubt that the laissez faire approach of the Genetic Supermarket communicates a negative value judgement to the disabled.

The first response to this contention did not involve any attempt to define to whom, or what, 'society' referred, simply because its central idea was that there was no negative judgement whatever; were this so, then the question of from whom precisely such a judgement originated is clearly meaningless. If this were not accepted, though, and if the

[51] Following the logic of the Non-Identity Principle, and assuming that Dresser, et al, are correct about the discontinuity of identity between those with, and those without, Alzheimer's, a somewhat more alarming prospect arises: that, in attempting to cure Alzheimer's, at least for those in the latter stages of the disease, we would in truth be seeking to replace one – existing – individual with a different, presently merely hypothetical one. If the discontinuity thesis is taken to its logical conclusion, would this amount to 'killing' one human being in order than another might come into existence? Of course, the same concern need not arise with regard to treatments which prevent the onset of Alzheimer's, or which arrest its progress in the very early stages; such treatments could either be regarded as the 'saving' of the existing life, or the choosing of one potential future life (that without Alzheimer's) over another, alternative future life (that with the disease). Which explanation one chose would,

expressivist objection were thought to possess some merit in relation to 'societal' messages, then it clearly becomes necessary to consider who or what 'society' describes in this context.

There are, I suggest, probably many different senses in which this term may be employed, but two in particular seem relevant to the present discussion. First, 'society' may be thought to apply to those individuals and bodies entrusted, elected or appointed to make decisions in the interests of the populace as a whole, while at the same time presumably safeguarding the rights and interests of minority groups or individuals within that populace; for the purposes of this debate, 'society' might be thought to be embodied in the decisions of Parliament, of the courts and of the HFEA.

The second sense in which 'society' might be thought to send any sort of message might take an even more direct form, as when individual women or couples made the same sorts of decisions in sufficient numbers to communicate a single message to a particular section of the population, in this case 'the disabled'. If the majority of women or couples faced with a choice elected to screen for and reject embryos affected with cystic fibrosis, this might be thought to convey a negative message to those living with CF as to how they are viewed by, and the extent to which they are valued or accepted within, the society in which they live.

This latter conception, I submit, may be dealt with in similar terms that I employed in addressing the objection in the preceding section. Disability activists like Marsha Saxton already appear (not implausibly) convinced that a free market in PGD would result in negative judgments about certain traits becoming the norm in practice. Yet if it is this judgement - not by any state or executive agency, court or quango, but by individual potential parents – that is offensive or devaluing to existing disabled persons, then we must ask whether we offer much solace by denying access to the means of implementing or demonstrating that judgement. Presumably some disabled persons will

presumably, depend on one's views on the degree of continuity of identity between the presently existing person,

still be aware, or at least highly suspicious, that such attitudes exist, and that the only reason they are not routinely implemented is that 'society' in its other conception – Parliament, the courts and the regulatory bodies – prohibit them from being so.

If the concern was that articulated by Tom Shakespeare or Susan Wendell earlier in this chapter, i.e. the practical concern that widespread use of PGD would reduce the proportion of disabled persons in society, then such a restriction may provide some comfort. But if the concern relates to the values underlying such choices, then it must be suspected that while denying the choice involves denying this particular means of demonstration, it does not alter the underlying value judgement. (Indeed, it is perhaps not unlikley that those denied access to what they now recognise to be a technologically possible option may demonstrate their value judgements in other forms, for example, by lobbying Parliament, appealing to the courts, writing to newspapers or – as in the case of the Whitaker and Masterton families – travelling to less restrictive jurisdictions to give effect to their choices. Perhaps most straightforwardly, it might be assumed that opinion polls and public consultations will continue to demonstrate wide public sympathy for abortion on the grounds of serious foetal abnormality, and PGD for 'serious inherited conditions'[52] a response that presumably conveys quite unambiguously the sort of value judgement some disabled persons find offensive.)

The notion, then, that we could prevent 'society' in the sense of the aggregate of potential parents from communicating negative value judgements by restricting their access to PGD is, I suggest, conceptually flawed. If the harm lies in their values rather than their actual choices, then in curtailing the choices we remove only one means of expressing those values, and not the offensive values themselves. Since it is likely that those values will continue to be expressed in other forms and through other media, and since it is likely that the more sensitive of observers will continue to *suspect* that such values exist in any event, it must be questionable whether a restriction in access to PGD

and the potential future (unaffected) individual into whom he might develop.

will address this particular concern. The only way in which 'society' in this sense could avoid the infliction of harm that lies in the mass rejection of disabled embryos would be by exercising that choice in a manner that does not devalue such embryos. Depriving them of that choice, at best, does no more than mask the offensive judgement, or more accurately – and perhaps more significantly – one of many possible manifestations of that offensive judgement.

What, then, of the role of 'society' in that other sense, i.e as embodied in the decisions, permissions and proscriptions of its decision-making bodies? Here, the response offered to the first sense of 'societal' criticism seems to have less validity. I have suggested that a ban on certain uses of PGD may do little to reassure disabled persons that they are not being devalued by the 'community of potential parents', since the only thing preventing them from acting according to those judgements is a system of legal restriction.

Presumably, though, the same thing cannot be said of the authors of these very restrictions. If Parliament elects to draw a line, permitting PGD for certain genetic traits or conditions but not for others, it is easy to see how this could be seen as a value judgement as between those traits or conditions. As Parens and Asch have said:

> Enlisting medical professionals to list the conditions approved for tests and exclude others as "not serious enough or burdensome enough" turns individual, private, parental decisions into socially supported ones. Also, it increases the likelihood that an explicitly devaluing message will be sent about people whose conditions are listed as "serious enough to avoid."[53]

And insofar as the decisions of Parliament (and perhaps of those bodies, such as the HFEA, to which it delegates a degree of decision-making authority) reflect the values of the society that elects them, then these decisions presumably reflect a certain sense of 'societal' judgements as to the value, or desirability, of the lives of those who possess the traits which it permits to be screened out.

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[52] Approximately 69% of respondents to the HGC/HFEA Public Consultation on PGD agreed that PGD should be available only where there is a known family history of serious genetic disorder or to cases of aneuploidy. 'Analysis of the Responses to the Joint HFEA/ACGT Consultation Paper on PGD', at para. 16.

[53] Parens and Asch. 'The Disability Rights Critique of Prenatal Testing', loc. cit., at pp.30-31.

At present, the HFEA allows PGD for the purpose of avoiding cystic fibrosis, but refuses to allow it for, say, avoiding a child with brown rather than blue eyes.[54] Assuming that the debit side of the equation – the reasons *against* allowing PGD, such as the intrinsic value attributed to the embryo, or the dangers inherent in the procedure – remain constant in both decisions, the justification for the differing response to these two uses of PGD must reflect a particular judgement as to the desirability of avoiding, respectively, children with CF and children with blue eyes. This judgement may rely on beliefs about the burdens such children may themselves experience, the burdens their births will impose on their parents, or the contribution they will be able to make to their 'society', but it seems that some such belief is implicit in this act of line-drawing; and it is precisely in such beliefs that commentators like Saxton and Wenders discern an offensive message.

Supposing, however, that the role of 'society' (as embodied in Parliament or the HFEA) in the decision of which traits to 'screen out' was wholly value neutral; that is, if the choice were entirely that of the prospective parents. In such a circumstance, I submit, we could reasonably conclude that 'society' sends no message to anyone, beyond the message that it is willing to respect the individual choice of individual potential parents in such matters. (The question of the extent to which it should adopt a facillitatory or enabling role, providing the means for prospective parents to make such decisions, will be considered in the next section.)

Is the role of society in such decisions really as passive as this contention seems to require? At present, in the UK, this is certainly not the case. As I discuss throughout this thesis, the availability of PGD is strictly curtailed by the terms of the Human Fertilisation and Embryology Act, and by the requirement of licensing by the Human

[54] I acknowledge that this is what may be termed a 'frivolous' choice, and one which few prospective parents might be thought likely to make, but I believe it illustrates my present point well as other possible considerations in support of restriction – such as might arise in relation to selection for sex, race or sexual orientation – do not arise to cloud the issue. In particular, and as distinct from those other attributes, I am aware of no serious discrimination in UK society on the basis of eye colour.

Fertilisation and Embryology Authority. PGD is available only for those traits that the Authority permits to be screened, and to date it has sought to restrict this to those likely to pose 'a significant risk of a serious genetic condition being present in the embryo'.[55] Furthermore, it has explicitly excluded screening on the grounds of embryonic sex or for HLA compatibility alone (although the latter decision was recently reversed; see Chapter 5).

What message does the Authority send out when it restricts the use of PGD in such a manner? All other considerations aside, it assuredly sends the signal that choices about PGD are not wholly private matters, to be arrived at by the prospective parents alone. Rather, it is making a statement to the effect that some choices prospective parents may make are acceptable, while others are not. As Reinders has said:

> Society does not allow us absolute freedom in any area of social life. ... Free choice, therefore, is always restricted to publicly acceptable uses of freedom. ... Consequently, if society accepts the prevention of disability as justified, it is because and only because it is regarded as a legitimate use of personal freedom. ... Our society considers prevention to be morally acceptable.[56]

PGD, then, will be permitted only where there is a sufficiently compelling justification for so doing. A fuller discussion of the implications of these conditions will be undertaken in the next chapter, but for present purposes it is relevant to consider the possible implication of restricting PGD to 'serious genetic condition[s]'. If there is merit in the objection that 'society' sends out negative signals to disabled persons when it allows prospective parents to screen them out of existence, then how much reinforced is that message when 'society' expressly prohibits every other kind of screening?

The details of the HFEA's approach to tissue typing will be considered in the following chapter, but it is informative for present purposes to note that the essence of the Authority's decision to allow the technique to be used by the Hashmis, but not by the Whittakers, lay in its belief that only in the former case could PGD be said to benefit the

[55] Joint Working Group of the HFEA and Human Genetics Commission, *Outcome of the Public Consultation on Preimplantation Genetic Diagnosis*, November 2001, Recommendation 11.
[56] Reinders, *The Future of the Disabled in Liberal Society*, op. cit., at p.64.

future child; when it is used only for tissue typing and not for the detection of genetic disease, then it violates the Kantian imperative against using people as means only, and not treating them also as ends in themselves.

I will argue in the next chapter that the distinction drawn between the two cases was premised on a questionable interpretation of the imperative, and that it was, ultimately, spurious. The important point for this chapter, however, is that the HFEA clearly regarded the use of PGD in the Hashmi case as being for the benefit of the future child. Given that there was no prospect of curing beta thalassaemia, this could only be taken to mean that the potential future Hashmi child possessed some kind of interest in avoiding being born with the burden of this disease. Yet what message does this decision send to Zain Hashmi, or to others who live every day with that same illness? A clearer example of PGD sending a societal message that 'it would have been better had you not been born' would be hard to find.

If, in contrast, Parliament and/or the Authority were to permit any prospective parents to screen for *any* trait, whether or not it is associated with what is conventionally seen as a 'disability', then it would be possible to argue that the value 'society' is upholding is that of reproductive choice, whatever that choice may be. As regards the specific choices which those prospective parents make, they could with some plausibility argue that they are entirely neutral; it would, after all, be difficult to argue that 'society' was implicitly devaluing the 'disabled' if it allowed couples like Duchesneau and McCullough to select genetically deaf embryos for implantation.

Clinical geneticist Angus Clarke espoused what is probably the orthodox line with regard to PGD when he wrote that 'society must determine what types of disorder are sufficiently severe to warrant prenatal-screening programmes with the termination of "affected" pregnancies.'[57] However, in allowing screening only to eliminate conditions

[57] Angus Clarke, 'Response to: "What counts as success in genetic counselling?"', *Journal of medical ethics* (1993); 19: 47-49, at p.48. See also Jeffrey Botkin: 'As the range of conditions for which we can test prenatally

deemed 'sufficiently severe', it may be that some validity is accorded to the arguments of those who, like Marsha Saxton, feel that their society is making a statement that they are unwanted. This is one concern about PGD which the laissez faire approach of the Genetic Supermarket might, in fact, address rather than exacerbate. The state's acceptance of PGD to screen out CF, Duchenne muscular dystrophy or beta thalassaemia embryos would, perhaps, seem less value-laden, less offensive, perhaps even less sinsiter to those living with such conditions were it also to accept the use of PGD to screen out embryos who had blue eyes, who were boys, or who had normal hearing, however much media hysteria was generated by such choices.[58]

4.3 The need for line-drawing?

A value-neutral approach to PGD, then, could circumvent at least some expressivist objections. Does such an approach, though, require that all potential parents have access to all possible preimplantation tests? And if not, how might a line be drawn between those which are available and those which are not?

Jeffrey Botkin is one of the few authors to have not only attempted to make the case for line-drawing in preimplantation and (particularly) prenatal testing, but to demonstrate where, or at least on what basis, such lines might be drawn. In a series of articles,[59] he has attempted to make the case that limits must be set on the range of genetic traits for

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expands, society and the medical profession need to develop guidelines about which tests ought to be offered and which ought not to be.' 'Fetal privacy and Confidentiality', *Hastings Center Report* (1995); 25(5): 32-39, at p.32.

[58] It may, of course, be suggested that in adopting an ostensibly laissez faire approach, the state would in reality be importing subtle value judgements. This might be so if its decision were in actuality premised on the assumption that the overwhelming majority of PGD-users would in fact use it to screen out 'disabilities' and not more 'frivolous' traits, still less to use it to screen *for* disability. Is it reasonable to contend that, in adopting a laissez faire approach in circumstances wherein it knows that a particular choice will be particularly prevalent, the state is tacitly endorsing only that choice? I suggest that this need not be so. Were the state to extend exactly equal legal status to heterosexual and homosexual relationships, it could plausibly argue that it was adopting a position of neutrality as between sexualities, despite the fact that it is predictable that considerably more couples will choose the former rather than the latter. Similarly, it need not undermine the constitutional commitments of the French and US states to neutrality on the question of religion that, in practice, a substantial majority of their citizens use, and have always used, that freedom to practise as Christians.

[59] 'Fetal privacy and Confidentiality', *Hastings Center Report* (1995); 25(5): 32-39; 'Line Drawing: Developing Professional Standards for Prenatal Diagnostic Services', in Parens and Asch, eds. *Prenatal Testing and Disability Rights*, op. cit., pp. 288-307; 'Prenatal Diagnosis and the Selection of Children' *Florida State University Law Review* (2003); 30: 265-293.

which testing should be available, according to both practical and ethical considerations. The practical aspect of his argument relies on the prediction that, as information about genetics expands, so to will the range of possible tests which might be carried out on an embryo's genome, expanding perhaps to encompass thousands of traits of varying degrees of rarity, and thousands of tests with varying degrees of accuracy. How, Botkin asks, is it 'remotely feasible' for a doctor or genetic counsellor to have a 'meaningful conversation' with a pregnant, or prospectively pregnant, woman about 'thousands of rare conditions'?[60]

On Botkin's model, the line between those tests which would be 'available', and those which would not should be drawn according to two criteria: 'risk' and 'value'. The former would reflect the likelihood of the trait which the test is intended to detect actually existing; for Botkin, the cut-off point might be where there is 'a prevalence of less than one in a thousand or one in ten thousand births ... below which physicians need not offer prenatal testing for the condition as standard care.'[61]

The second criterion employed by Botkin in his line-drawing exercise is 'value', that is, the impact a given condition will have on 'family life'.[62] Impact, he suggests, can be measured in terms of four characteristics: 'the likely severity of the condition with respect to health', 'the age of onset of the condition', 'the probability that the child's genotype will manifest as a significant clinical disease' and 'the probability that the condition will occur in those without specific risk factors.'[63]

It is in this attempt at value-based line-drawing that Botkin, as he acknowledges, encounters difficulties; first with relevance to the lack of consensus on the relative 'severity' of various traits. Although he is doubtless correct in his observation that

[60] 'Line Drawing: Developing Professional Standards for Prenatal Diagnostic Services', loc. cit., at p.295.
[61] Ibid, at p.297.
[62] Note that Botkin's approach is concerned primarily with prenatal testing, and hence, his approach is premised substantially upon an analogy with abortion for 'social' reasons. Thus, he asks not just how the condition will impact upon the child – as he points out, conditions such as anencephaly or Down syndrome may not be 'bad' for the child - but whether and to what extent it will harm the family.
[63] Botkin, 'Fetal privacy and Confidentiality', loc. cit., at p.37.

certain conditions, such as Tay-Sachs, would be regarded as very severe by almost anyone familiar with their symptoms, identifying one extreme does not provide much assistance with drawing lines.

In attempting this line-drawing, Botkin attempts to draw analogies between the burdens imposed by unwanted children and by disabled children; if, he argues, we allow abortion on 'social' grounds where women are too young, or too poor, or simply too reluctant to bear these children, then the cut-off point for allowing genetic testing should be where the disability in question would impose 'problems for the parents of a similar magnitude to the birth of an unwanted child.'[64] Which genetic conditions, he enquires, would be approximately as burdensome on a family as an unplanned and unwanted child?

Specifically, he identifies 'conditions that are often fatal in childhood', 'conditions that result in a child who is chronically ill or who has recurrent illnesses of sufficient gravity to require repeated hospitalization', 'conditions that will not permit the child to achieve independence in his or her adult years' and 'disabilities of such severity that there are constant demands on the parents for time, effort, and financial resources'.[65] He would exclude, however, 'any condition affecting children that can be cured or effectively treated so that the affected individual does not experience significant mental or physical impairments and in which the cure or treatment does not cause a serious financial burden to the family';[66] 'those conditions affecting children that may not be amenable to cure or effective treatment, but for which some treatments may be available or the conditions

[64] Id.

[65] Id. Botkin then goes on to enumerate specific genetic conditions that he believes meet his criteria, including 'hemophilia, Down syndrome, sickle cell anemia, Menkes syndrome, Fanconi's syndrome, fragile X syndrome, muscular dystrophy, osteogenesis imperfecta, Hurler's syndrome, cystic fibrosis, Tay Sachs disease, many cases of spina bifida, and many inborn errors of metabolism. The burdens of these conditions for the parents are roughly similar, if not much greater, than the burdens of an unwanted child in terms of the effort, time, and financial resources necessary to care for these children, not to mention the tragic early deaths caused by some of these diseases.' At p.38.

[66] 'Examples would include PKU, galactosemia, polydactaly, hypothyroidism, most cases of asthma, and cleft lip and palate.' At p.38.

usually have a limited impact on the life of the child and family in terms of effort, time, and financial resources';[67] and 'those conditions that do not affect children'.[68]

Assuming that Botkin's prediction is correct, and it does become possible to test for thousands of traits, what implications might this have for the Genetic Supermarket hypothesis? In particular, would it in fact necessitate an exercise in line-drawing? At different points in his argument, Botkin seems to offer at least two different, and potentially mutually irreconcilable, answers to the question of why there is a need for line-drawing at all. On the one hand, he appears to argue that prenatal testing is inherently ethically problematic and therefore in need of justification. At one point, he contends that 'the knowledge that our parents fashioned us to their liking' is potentially harmful, offending against 'a personal sense of independence and individuality'.[69] He goes on to argue that 'other values, such as respect for prenatal life' must be weighed in the balance against 'the welfare of prospective parents'.[70]

In Chapter 3 of this thesis, I sought to address both of these objections to the Genetic Supermarket hypothesis, but if these do constitute genuine (or plausibly likely) harms then it would be entirely right to argue that a weighty case must be made out for permitting genetic testing, and it may well be correct to argue that some tests would outweigh this harm while others might not. However, at other points in this chapter, Botkin himself seems to take the view that these are not sufficiently weighty harms to require a prohibition of those tests which do not meet his criteria, but merely that tests for these 'below the line' conditions should not be *required*. In the final paragraph of his conclusions, he says the following:

> My conception of a line corresponds to a professional standard of care, not legal prohibitions on the provision of services. ... Practitioners could choose not to conform to the standard, by offering either more or less testing than the standard (although they

[67] 'Examples include G6PD deficiency, many of the thalassemias, Tourette syndrome, spherocytosis, Marfan syndrome, and ichthyosis vulgaris.' Id.
[68] 'including Huntington disease, polycystic kidney disease, and many of the hereditary predispositions to cancer, such as those secondary to the BRCA1 gene.'
[69] 'Line Drawing: Developing Professional Standards for Prenatal Diagnostic Services', loc. cit., at p.302.
[70] Id.

> could be held legally liable through wrongful birth suits for failure to provide sufficient information).[71]

Yet if Botkin's argument is that line-drawing is required because the harms inherent on below-the-line tests require to be outweighed by competing harms, it is difficult to see why the provision of such tests should be at the discretion of practitioners.

Considerably more plausible, I suggest, is his claim that it is impractical to provide all possible tests, or even information about all possible tests, to all prospective parents. If his prediction is accurate, and it does in future become possible to test for thousands of conditions, is it necessary to allow access to every possible test to every prospective parent?

The answer to this question depends very much on what, precisely, it is asking. If the question is whether the state (in the form of the criminal law and licensing bodies like the HFEA) should *restrict* access to PGD, then I have already suggested a negative response to this (subject to a very few rare exceptions). If, on the other hand, it is asking whether the state (via the auspices of the NHS) should be subject to a *positive* obligation to provide access to PGD, even for incredibly rare conditions (where there is no reason to suspect heightened susceptibility) or 'flippant' choices, then two distinct options arise. The first is what we might refer to as a 'hard' conception of the Genetic Supermarket. This would propose that, while potential parents could avail themselves of whatever tests they wished, free from state interference, access to such tests would not be provided for them by the state. If the state will not pay for *any* PGD, then we need not concern ourselves with the task of specifying *which* tests it will provide.

On an alternative, 'soft' conception of the Genetic Supermarket hypothesis, the state's obligation would not only be negative – to refrain from interference – but positive – to provide the means to act on those choices. Assuming that neither the public will nor the practical means would provide access by *anyone* to *any* possible test, such a model would necessitate an exercise in line-drawing akin to that attempted by Botkin. As such,

[71] Ibid, at p.306.

it would leave itself open to two charges. The first contends that any such lines would, in the absence of any consensus as to 'severity', be arbitrary. While the other three of his criteria rely on objective judgements (though we might question the accuracy with which they can presently be made), 'severity' denotes a subjective value judgement, about a matter on which there is no underlying agreement within the medical profession or among those affected by those conditions or their families or carers.

Botkin seeks to circumvent this absence of consensus by reliance on what most parents might be assumed to deem intolerably burdensome; his line will reflect 'prudent standards of care', and not the 'idiosyncratic or highly subjective expectations'[72] of a few parents. Yet there is reason to doubt any generalisation as to the extent of the familial burden imposed by a particular condition. Philip M. Ferguson, Alan Gartner and Dorothy K. Lipsky, writing in the same collection as Botkin, refer to research that casts serious doubt on widespread assumptions about how disabled children impact upon pre-existing families, while several authors – including Deborah Kent, Alison Davies and Hans Reinders - have pointed to the disjunction between the perception of life with a given disability shared by those with direct experience of it, and the perception held by the public at large. For such writers, it seems likely that Botkin's line would be set at too low a level, designating some conditions 'sufficiently severe' which, they would argue, are entirely compatible with a good standard of life, both for the affected child and the family into which it is born.

On the other hand, as discussed in Chapter 3, bioethicists including John Harris and Julian Savulescu argue for an ethical obligation to avoid, as far as is possible, any condition which would 'harm' a future child. For such influential academics, it would seem that Botkin's line would be set too high, excluding a great many harmful conditions.

[72] 'Fetal privacy and confidentiality', op. cit., at p.37.

And then there are those potential parents who actively seek children who would, on Botkin's analysis, fall on that side of the line for which testing should be available. What of the couple of very restricted height who wish to avoid the birth of a child who will soon grow big enough to present practical problems for their domestic arrangements?

A 'soft' conception of the Genetic Supermarket, then, wherein the choices of prospective parents would not only be permitted but would be funded by the state, would necessitate an exercise that would certainly not please all interested parties, and would inevitably be open to the charge of arbitrariness. Furthermore, such an exercise would expose the line-drawers (presumably the HFEA or some similar body) to the expressivist objections considered earlier in this chapter.

There is one more sense in which the question of whether lines are needed might be interpreted. This would see it as asking which tests should be routinely offered by practitioners, in the sense of informing prospective parents as to their availability. The question is really asking: do the dictates of good clinical practice require that practitioners alert their patients to options which may be available privately, but which will not be provided by the NHS? Is it even possible that a practitioner who fails to inform a prospective parent of her options in terms of self-funded PGD may leave himself exposed to a delictual claim, either in negligence or for 'wrongful birth'? Although somewhat beyond the remit of this thesis, such possible adverse outcomes will be considered in the final chapter.

4.4 Considerations of justice

One means by which the 'arbitrariness' and 'expressivist' objections could be avoided, then, would be by the state declining to fund any uses of PGD - what I describe as the 'hard' conception of the Genetic Supermarket hypothesis, and, I surmise, the conception that would come closest to Nozick's ideal. This laissez faire approach, then, may allow the state to profess neutrality as between different choices, and hence between the qualities of different lives. As such, it may address some of the concerns of disabled

persons that their lives are being 'officially devalued'. However, this approach inevitably gives rise to another kind of possible concern: a system wherein PGD would be available only to those wealthy enough to afford it seems to sit uneasily with many notions of justice.

4.4.1 Injustice as a species of harm

Before considering the possible impact of such a 'free market' approach to PGD for the notion of justice, the question arises as to whether such concerns properly fall within the remit of this thesis. The question of justice arose briefly in Chapter 2, but the question of whether it properly belonged within a harm-based consideration, or whether it in fact stood alone as a separate ethical principle[73] or moral axiom[74] was at that time unexplored.

That justice may be thought to possess some intrinsic value may be regarded as uncontentious. Can we, though, say of someone who has been treated unjustly that he has been harmed thereby? In some instances of injustice, this will clearly be so -- when the injustice frustrates or sets back one or more of his interests. Whether we can say the same of the case where an unjust action leaves no-one worse off than before is less certain. A decision to open the doors of the Genetic Supermarket only to those who can pay their way might be deemed unjust; but those denied entry have, arguably, been deprived of nothing which they previously possessed. Is it meaningful to say that they have been harmed?

One response would be to contend that they have indeed been deprived of something they previously possessed; the knowledge that they are being treated justly or fairly. The status quo ante might have denied them access to PGD, but they could comfort themselves with the knowledge that that restriction was applied even-handedly. The

[73] Tom L. Beauchamp and James F. Childress, *Principles of Medical Ethics*, Fifth Edition, New York, Oxford University Press, 2001.
[74] Jonathan Glover, *Causing Death and Saving Lives*. London, Penguin Books, 1990

knowledge that others were, by virtue of their preferential economic position, able to access this technology may render that exclusion so much harder to tolerate.

It may also be the case that an approach that allows access to PGD only to those who can afford it will perpetuate certain divisions in society in a manner likely to be to the detriment of those who are already treated unjustly. The following section will consider some such claims.

4.4.2 What does justice require?

'Justice' has many different meanings, one of which – the notion that people should not be blamed for factors over which they exerted no control - has been discussed already in this chapter. The idea of justice that gives rise to the species of objection considered here is related to that concept, but is an expanded version thereof. The notion of justice that might be thought contravened by the adoption of a Genetic Supermarket approach is one that proclaims it unfair that PGD should be available only to those who can afford to pay for it, and furthermore, that it thereby exacerbates the divide between those who already occupy a privileged position in society and those who are less privileged.

The former objection is similar to that which could be levied against any private 'healthcare'; an objection that proclaims it unfair that only the wealthy should be able to access that which is not available to all. This is the kind of concern that has led Buchanan, Brock, et al to the conclusion that 'If equality of opportunity matters, then we cannot assume that an unregulated "genetic supermarket" is legitimate.'[75]

The second objection is more concrete, proclaiming that, in one way or another, the availability of PGD only to the wealthy will actually damage the less wealthy. This concern was perhaps most vividly expressed by journalist and author George Monbiot:

> Just as the escape hatch of the public school enables the wealthiest and most influential people in the country to ignore the under-

[75] Buchanan, Brock, Daniels, Wikler, *From Chance to Choice: Genetics and Justice*. New York, Cambridge University Press, 2000, at p.99.

> funding of state education, future genetic screening or gene therapy could allow them to buy their way out of concern for the social and environmental factors which contribute to poor health. Indeed, it's not hard to imagine a future in which only the rich could - through gene technology - escape from the genetic effects of increasing exposure to such pollutants as pesticide residues and radioactive waste.[76]

Phillip Kitcher has couched his concern in similar terms:

> If prenatal testing for genetic diseases is often used by members of more privileged strata of society and far more rarely by the underpriviliged, then the genetic conditions the affluent are concerned to avoid will become far more common among the poor - they will become "lower-class" diseases, other people's problems. Interest in finding methods of treatment or for providing supportive environments for those born with the diseases may well wane.[77]

This leads Kitcher to the conclusion that 'societies that introduce prenatal testing have a moral obligation to work toward making it available to all their citizens.'[78]

It might be thought that this concern has many similarities to that articulated by Tom Shakespeare, and considered earlier in this chapter. Where Shakespeare argued that a reduction in the numbers of disabled people would lessen societal concern for those who are still born with those diseases, Monbiot and Kitcher are more concerned with the distribution of these disabling genes. If they are reserved almost exclusively to the less wealthy – and by implication, probably the less influential – members of society, then it is perhaps unlikely that the resources necessary to treat the symptoms of those conditions, or to provide a more accessible environment for those affected by them, will be made available.

As with Shakespeare's argument, we might accept the merits of this contention while wondering how precisely it might be addressed without causing greater harms. It may very well be that the best way in which to ensure that society as a whole is concerned about certain disabilities is by ensuring that those disabilities are themselves shared

[76] George Monbiot, 'Rock-a-bye baby with the perfect genes', *The Guardian*, 18 February 1997.
[77] Philip Kitcher, *The Lives To Come*, Allen Lane, The Penguin Press, 1996, at p.198.
[78] Ibid, at p.200.

throughout society. But how is such an equitable distribution of disability to be effected? The most obvious solution, it may be thought, would be by declaring that if PGD cannot be afforded by all, then it should be available to none. This would certainly promise to prevent the economically privileged from ensuring that they are also the 'genetically privileged'.

Yet such an approach contains certain disadvantages, some of which may be deemed insurmountable. First, it involves a necessary and substantial interference with the interest in reproductive choice possessed (by definition) by those who would otherwise have used this technology. Of course, it might be argued that any compulsory redistributive measures, including taxation, involve an interference with liberty interests. Yet, for reasons discussed in Chapter 2, it might be thought that interference with the interest in reproductive liberty, in denying someone control over what sort of child for whom they will spend the next twenty (or, in the case of profoundly handicapped children, perhaps many more) years bearing a burden of responsibility, we interfere with their interests in a much more profound way than when we requisition and redistribute some of their earnings.

Furthermore, it has been suggested that the use of PGD even if only by the wealthiest sections of society could provide incidental but nonetheless substantial benefits to the less wealthy. Ronald Dworkin has argued that 'even a diminished demand for a particular therapy will stimulate research, with possibly unanticipated general benefits, that would not otherwise take place.'[79] Such a technological trickle-down effect might be thought unlikely when the effect for those who can afford it is to avoid the birth of affected children, rather than to develop better or cheaper ways to assist or treat them, but it is perhaps not inconceivable that, with repeated use, the technologies of the Genetic Supermarket will become more effective and, hence, more affordable. It is possible, for example, that IVF itself will become more effective, in many cases obviating the need for repeated attempts at conception or successful implantation. This

[79] Ronald Dworkin, *Sovereign Virtue*, op. cit., at p.437.

may bring the technology within the reach of those who could not afford repreated cycles of treatment, but who could perhaps afford one or two such attempts.

Whether or not such a result would occur, Dworkin's liberal position is that 'rich people' should in any event be allowed to purchase treatments that the state will not provide for everyone; 'We do not in general seek equality by leveling down'.[80] Rather, 'The remedy for injustice is redistribution, not denial of benefits to some with no corresponding gain to others.'[81] Examples of the application of Dworkin's approach are not difficult to find. When it is established that a good diet is related to health and longevity, and further established that, in a given society, not everyone can afford a good diet, the efforts of progressives are not aimed at gratuitously denying good food to the wealthy but at ensuring that the underprivileged too have access to it. In relation to PGD, then, those concerned with justice should, according to Dworkin, be concerned with ensuring that it is available to all, and not denied to those who can at present afford it.

4.4.3 'Silver spoons' and 'Golden genes'

George Monbiot has drawn an analogy between 'choosing your children's genes' and 'choosing to educate them privately', both choices that he regards as pernicious.[82] While in certain respects this analogy may be inexact,[83] one aspect that both choices may be thought to possess in common might be troubling for those concerned with 'justice'.[84] By sending their children to fee-paying schools, parents generally attempt to bestow upon them a competitive advantage over their peers. Since, by definition, fee-paying schools are only open to those who can afford them, and the more renowned of them

[80] Id.
[81] Ibid, at p.440.
[82] George Monbiot, 'Rockabye baby with the perfect genes', loc. cit.
[83] It is, for one thing, easier to argue that prospective mothers have a strong personal interest in determining which of their ova should be reimplanted in their uterus than to argue for a strong personal interest in controlling the education of someone who is, by that stage, a separate individual, with his or her own interests. Even Mill did not argue that individual liberty should extend to making controlling decisions over ones children.
[84] Such criticism of fee-paying schools has a lengthy tradition among socialists and those concerned generally with issues of justice. For example, in 1943, R. H. Tawney wrote that 'Given the existing economic order, sharp class divisions exist independently of educational organization and policy. ... It is difficult to deny that the tendency of those schools is to deepen and perpetuate them.' 'The Problem of the Public Schools', first published

only affordable by an affluent minority, it might be thought that these schools seek to exacerbate or reinforce the already privileged position of those who attend them, shoring up their inborn economic advantage with a high quality education and a potentially lucrative network of contacts for later life. Thus, economic and class divisions are reinforced.

In a similar manner, a Genetic Supermarket affordable only by the already wealthy would complement the economic advantages with which certain children would be born with a series of genetic advantages; they would, in the words of one commentator, be born not only with 'silver spoons' in their mouths, but with 'golden genes' in their chromosomes.[85] Such an objection might become more pronounced were knowledge about genes to extend beyond the identification of the genetic cause for certain diseases, and begin to identify – as many writers have predicted – genetic predispositions to other non-disease attributes such as above-average mental functioning or sporting prowess. Were refinements in PGD to advance in parallel, allowing such traits to be identified in vitro, what would stop a wealthy couple electing to choose a daughter with above-average aptitude in music, or a son with a gift for mathematics?

One limiting factor, of course, would be whether such abilities were already latent in the gametes of the wealthy couple. The use of PGD, after all, is not an example of what is sometimes deemed 'genetic enhancement'; unlike genetic modification, it cannot add anything to or remove anything from the genes possessed by the couple's embryos. Thus, the selection of traits that will be open to them will be limited by what their own genes already contain. Unless wealthy people generally have a higher genetic aptitude for maths or music than those less economically advantaged, as opposed to advantages resulting from relatively privileged upbringing and education, it is unlikely that they will routinely be able to guarantee their children 'golden genes', or even 'silver genes'.

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in *Political Quarterly* April/June 1943, more recently in *RH Tawney: The Radical Tradition*, ed. Rita Hinden, Middlesex, Penguin Books, 1964, at p.63.

However, while they may not be able to guarantee such attributes, the ability to choose between numerous 'candidate embryos' will, perhaps, enable them to maximise the likelihood that any potential for genetic abilities latent in their gametes will be actualised. If it transpired that there was a genetic trait predisposing affected children to higher-than-average musical ability,[86] but that the genetic trait in question was recessive rather than dominant, then only one in every four embryos would be expected to possess that trait; PGD would allow the couple to avoid 'squandering that potential' by inadvertently implanting one of the other three embryos. And since it is likely that, in reality, any such genetic predisposition will be of a far more complex nature, involving the interaction of various different genes, the likelihood of stumbling across the right combination by chance would very probably be considerably longer than one in four.

Wealthy couples, then, may not be able to guarantee their children golden genes, but – to stretch the metaphor – they may be able to identify hidden seams that would be invisible to those excluded from the Genetic Supermarket. Should this be a cause of concern?

Throughout his life, John Rawls, one of the most renowned theorists in the field of distributive justice, repeatedly addressed the question of inequality of talent. In his most influential work, *A Theory of Justice*, Rawls proclaimed that 'No one deserves his greater natural capacity nor merits a more favourable starting place in society'.[87] Rawls later described the idea that we do not 'deserve' our natural endowments as a 'moral truism',[88] asking rhetorically:

> Who would deny it? Do people really think that they (morally) deserved to be born more gifted than others? Do they think that they

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[85] Hillel Steiner, 'Silver Spoons and Golden Genes', in Justine Burley, ed. *The Genetic Revolution and Human Rights*, Oxford, Oxford University Press, 1999, pp.133-151.

[86] It has been suggested that perfect pitch may have a strong genetic basis; see R. Ashcroft, 'Bach to the future: response to: Extending preimplantation genetic diagnosis: medical and non-medical uses.' *Journal of Medical Ethics* (2003); 29(4): 213-6

[87] John Rawls, *A Theory of Justice. Revised Edition.* Oxford, Oxford University Press, 1999, at p87. See also Thomas Nagel: 'to sever the connection between talent and income, if it could be done, would be fine. Those with useful talents do not naturally deserve more material benefits than those who lack them.' *Equality and Partiality*, Oxford, Oxford University Press, 1991, at p.113.

[88] John Rawls. *Justice as Fairness: A Restatement*, Cambridge, Mass.; London, The Belknap Press of Harvard University Press, 2001, at p.74.

> (morally) deserved to be born a man rather than a woman, or vice versa? Do they think that they deserved to be born into a wealthier rather than into a poorer family?[89]

This uncoupling of talent and desert has been considered earlier in this chapter, and I assume it to be relatively uncontroversial. Of more interest for present purposes is how Rawls proposed that such an undeserved disparity of talent should be redressed. For acknowledging that such differences are undeserved does not lead Rawls to conclude that a just society must strive 'to ignore, much less to eliminate these distinctions.'[90] Rather, such differences can be accommodated within a fair society by ensuring that 'the basic structure can be arranged so that these contingencies work for the good of the least fortunate.'[91]

Much of the remainder of Rawls' work is dedicated to outlining what form such a structure might take. For present purposes, though, what is significant is his recognition that 'The natural distribution is neither just nor unjust ... What is just and unjust is the way that institutions deal with these facts.'[92] Indeed, in other passages Rawls seems to suggest that a disparity of talents is something to be cherished rather than challenged:

> The difference principle represents, in effect, an agreement to regard the distribution of natural talents as in some respects a common asset and to share in the greater social and economic benefits made possible by the complementarities of this distribution. Those who have been favoured by nature, whoever they are, may gain from their good fortune only on terms that improve the situation of those who have lost out.[93]

In a society devised along Rawlsian lines, then, the prospect of wealthy parents endowing their offspring with advantageous genes would not necessarily be incompatible with justice. This is so because (a) society would redress this imbalance by 'giv[ing] more attention to those with fewer native assets and to those born into the less favourable social positions';[94] (b) because '[t]hose who have been favoured by nature ...

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[89] Rawls, *Justice as* Fairness, op. cit., at pp. 74-75.
[90] John Rawls, *A Theory of Justice*, op. cit., at p.87.
[91] Id.
[92] Id.
[93] Id.
[94] Ibid, at p.86.

may gain from their good fortune only on terms that improve the situation of those who have lost out.';[95] and (c) because in any event, remuneration in such a society would be 'according to effort, or perhaps better, conscientious effort'[96] rather than 'rewarding people for that over which they had no control'.[97]

In a similar vein, Michael Albert, influential proponent of Participatory Economics, has advocated that a fair society would be one in which disparities in remuneration would exist only insofar as there were disparities in the degree to which individuals were willing to make sacrifices, in terms of their time or effort, but in terms of natural ability, the aggregate products of labour would be divided equally.[98] In a society modelled along such lines, the introduction of an uncommonly talented individual would not widen the gap between the already fortunate and the already unfortunate, but would raise (by however small a degree) the standard wage paid to all.

Yet the societies in which we actually live are not modelled along the lines of Rawls' difference principle or Albert's participatory economics, but at least purport to reward talent rather than effort. We live in an age where 'celebrities' routinely receive millions of pounds a year, not only for whatever talents they may possess (attributable at least to some degree to the effort expended in practicing or rehearsing) but for their 'marketability', a quality borne largely of their perceived aesthetic attributes. Is it any comfort to know that justice dictates that such unchosen and undeserved qualities *should* not bestow advantage, when every day we see irrefutable evidence that they *do*?

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[95] Ibid, at p.87.

[96] Ibid, at p.274. Rawls notes, however, 'that the effort a person is willing to make is influenced by his natural abilities and skills and the alternatives open to him.'

[97] Ibid, at p.274. Rawls notes, however, 'that the effort a person is willing to make is influenced by his natural abilities and skills and the alternatives open to him.'

[98] 'in a parecon remuneration is for effort and sacrifice. Since parecons equilibrate jobs for quality of life implications, rewarding for effort and sacrifice conveniently means that you earn more only by virtue of working longer or working harder, and that you earn less only by virtue of working less long or less hard, assuming, of course, that you are doing socially valued labor that utilizes assets effectively.' Michael Albert, 'Revolution Based on Reason Not Faith or Fantasy', 18 December 2003, available at http://www.zmag.org./ZNETTOPnoanimation.html

One possible response to this would be to ask whether simply restricting access to the Genetic Supermarket would make a substantial change to such unjust distributions of rewards. As things stand, the most fortunate members of society routinely pass on advantage, in one form or another, to their children, whether in the forms of the 'golden genes' which helped them attain that fortunate position for themselves, or in terms of the combination of economic, social and emotional advantages that often accompany birth into such an environment.[99] In allowing wealthy couples to test their embryos for what they assume to be the most advantageous genotypes, we certainly open up one more channel by which unearned advantage can be passed on, but even if this were denied, the existing channels are more than sufficient to ensure that their offspring receive a substantial head-start.

Is it really certain that selecting their children on the basis of their genotypes will prove a greater perpetuation of class division than the ability to provide 'private schools, culture in the home, a secure home environment, trips abroad, private lessons, an advantaged peer group, and successful role models'[100]? Myriad ways already exist by which wealthy or well-connected parents can imbue their children with undeserved advantage, many of which may be far more influential on their future prospects than PGD. Principles of distributive justice dictate that society should take cognisence of all such advantages, and act to ensure that those who were, through no fault of their own, denied them do not suffer unnecessarily as a result.

Similarly, though, those whose success in life is due to inate athletic prowess, artistic creativity or physical attractiveness are scarcely more deserving of the rewards these bring (except insofar as they must be coupled with actual effort). Denying the wealthy access to the Genetic Supermarket will not bring about a Rawlsian utopia where reward follows effort; it will, at most, perpetuate the status quo, ensuring that one undeserving

[99] The possibility that some children of high-achievers will be subject to greater emotional burdens must also be borne in mind, and has already been considered in Chapter 2. Nonetheless, the preponderence of evidence suggests that well-being – conceived in terms of academic and economic achievement, health and longevity – varies directly and not inversely with parental wealth.

elite benefits rather than another. If we are truly concerned with justice, we must act so as to ensure that those who lack the attributes necessary to excel in business, sport, the arts, or whatever other area upon which our society chooses to lavish the greatest rewards, should not be abandoned to poverty-line drudgery; whether the obstacles to their success were genetic or environmental, they were in any event not chosen or earned, and justice dictates that people should not be penalised for that which lies beyond their control. As the authors of one book on social class and justice have said: 'Luck *per se* may be ineliminable ... But why should it be just to permit the fact that some are lucky and others unlucky to influence the distribution of rewards in society?'[101]

Those who object that the laissez faire approach of the Genetic Supermarket is unjust must therefore demonstrate why it is any more unfair than the status quo. Their approach seems to favour a 'lottery ticket' approach to justice, according to which winners in the lottery may enjoy the fruits of their good fortune provided only that everyone was provided with an equal chance of winning. Thus, it is acceptable to reward winners in the genetic lottery, provided that the wealthy did not have the odds of winning stacked in their favour. Of course, the genetic lottery is not, of course, in any sense fair; parents who are carriers of genetic disorders are vastly more likely to have similarly affected children, while those with 'golden genes' are more likely to pass them onto their children. But even if it were fair in the sense that everyone had a similar chance of winning, winners would still reap the benefits of brute luck rather than of their own efforts or sacrifices. Whether or not the Genetic Supermarket approach is adopted, such undeserved advantage will exist.

There are various mechanisms by which society attempts to counter the unfair advantages that result from fortunate environmental factors. A substantial investment in comprehensive schools can help counteract the advantages bestowed by elite fee-paying schools. Inheritance tax can distribute what would have been unearned income

[100] James Fishkin, *Justice, Equal Opportunity and the Family*, New Haven, Conn., Yale University Press, 1983, at p.52.

accumulating in the hands of a small number of people. But even professed socialists seem reluctant to apply such measures to the inequalities borne of the genetic lottery.[102] For those concerned with egalitarian conceptions of justice, though, there can be no distinction in principle between unearned advantage of one sort or the other. Monbiot is correct in claiming that whether parents bestow advantage genetically or environmentally is a matter of ethical indifference; yet he stops short of acknowledging that it is equally a matter of indifference whether one gains a genetic head-start through the deliberate efforts of one's parents, or through the chance outcomes of the genetic lottery.

4.5 Depriving society of valuable contributors

An objection that can, I believe, be dispensed with quite readily is that expressed, in these typically emotive terms, by Hubbard and Wald:

> I am glad Woody Guthrie was born, though he developed Huntington disease. I am glad for all the blind poets and musicians, from Homer to Stevie Wonder. Who knows, maybe Helen Keller would have led a completely undistinguished life instead of becoming a famous writer and political activist had her immune system not failed as a child.[103]

As a statement of admiration for several talented though disabled individuals, this passage would be quite uncontroversial, but it is, perhaps, considerably less impressive as an objection to PGD or prenatal screening. That Hubbard and Wald intend it as such is made clear in their next paragraph, which concludes with the claim that 'No one, and no group of people have, in the words of Hannah Arendt, "any right to determine who should and who should not inhabit the world."'[104]

In drawing attention to the gifted artists who may never have been born had PGD been available to their parents, Hubbard and Wald's argument bears a close similarity to the 'Beethoven question', frequently employed as a rhetorical device on anti-abortion

[101] Gordon Marshall, Adam Swift and Stephen Roberts, *Against the Odds? Social Class and Social Justice in Industrial Societies*, Oxford, Clarendon Press, 1997, at p.165.
[102] See Alex Callinicos, *Equality*, Cambridge, Polity Press, 2000, at pp. 38-39 for some examples.
[103] Ruth Hubbard and Elijah Wald, *Exploding the Gene* Myth, Boston, Beacon Press, 1993, at p.161.

websites. There are several subtly different variations of this question, but most ask the reader to consider something like the following scenario:

> A professor at the UCLA Medical School presented the following case history to his students: A woman who suffers from tuberculosis is pregnant. Her husband has syphilis. There are three children in the family. One is blind, another deaf, and the other suffers tuberculosis. Yet, another child died in infancy.

When the students predictably retort that they would recommend abortion, the professor replies 'Congratulations, you've just killed Beethoven!'[105]

It does not require much in the way of ethical analysis to show up some of the weaknesses of this hypothetical as an argument against abortion, but it is if anything even more precarious as a case against PGD. First, while it is of course possible that, in 'selecting against' a particular embryo, prospective parents will inadvertently deprive the world of the next Beethoven it is, presumably, equally likely that the embryo they select in its place will be the genius. Unless Hubbard and Wald believe that 'disabled' persons are more disposed towards genius than the population in general – and they offer no support for such a contention beyond that short list of examples – then they would, presumably, concede that there is no basis for presuming that either embryo is more likely to develop into the next Beethoven than the other. In deciding *not* to abort this first pregnancy, in favour of some later non-disabled pregnancy, it is just as likely that they will be depriving the world of a future genius.

Were evidence to be led demonstrating that persons affected by particular genetic traits commonly deemed 'disabilities' were disproportionately inclined towards creativity or excellence in the sciences, then that position may change. But equally, we might expect that societal attitudes towards those conditions may also change; a genotype that predisposes the individual to exceptional talent in some or other field would not, we

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[104] Id.

[105] Anonymous, 'Abortion: The Silent Holocaust', at http://www.ecclesia.org/truth/abortion.html, viewed 12 August 2004. Other examples can be found in Glen A. Stocker, 'What God Says About: Abortion Verses Pro-life', at http://www.biblebelievers.com/Stocker1.html, and 'The Abortion Debate -- A Pro-Life Stance', at http://www.studyworld.com/moral_issues/abortion/abortion_debate_a_pro-life_stance.htm.

might expect, be viewed in a uniformly negative light, unless the disability that accompanied it was particularly severe.

Furthermore, it may be likely that the availability of techniques like PGD will in fact increase the chances of the next Beethoven or Woody Guthrie being born, simply by virtue of enabling certain people to become pregnant who would otherwise have been unable to give birth to any child because of conditions such as aneuploidy, or by encouraging others who would be deterred from doing so by the prospect of passing on a genetic illness. As Angus Clarke has noted, 'many women in families with Duchene muscular dystrophy ... used to fear pregnancy and chose to have few children, if any, or to terminate all male fetuses.'[106] It seems self-evident that the chances of the next Beethoven being born will be higher if the option of reproduction is afforded to those potential parents who previously refrained from having *any* children.

Perhaps the most obvious reservation about the 'Beethoven argument', however, derives from the recognition that what it appears to be asking is for individual reproductive autonomy to be sacrificed in the interests of 'society'. While it is not unreasonable to seek to balance third party interests against those of the prospective parents – indeed, that is the point of this chapter – there is perhaps something uncomfortably reminiscent of the eugenics movement in a position that seeks to curtail individual reproductive freedom in the interests of (possibly) producing more gifted or productive offspring.

4.6 'Irresponsible reproduction'

The third party interests considered thus far in this chapter have in common that they have been argued to count as reasons to restrict access to PGD, if not to deny access to it altogether. There is, however, another species of third party interest that might be thought to pull in the opposite direction. The nature of this argument is expressed by Laura M. Purdy:[107]

[106] Angus Clarke, 'Genetics, ethics, and audit', *The Lancet* 1990; 335;1145, at p.1145.
[107] Indeed, it is difficult to find professional bioethicists who actually adhere to this view.

> Isn't it immoral to knowingly act so as to increase the demands on ... resources that could otherwise be used for projects such as feeding the starving or averting environmental disaster? Isn't attempting to avoid the birth of those who are likely to require extra resources, other things being equal, on a par with other attempts to share resources more equally?[108]

In a similar vein, Ingmar Persson has written of 'disabling diseases – perhaps like Down's syndrome' that 'may allow those afflicted, with some extra assistance, to lead lives that are reasonably good for them, but will rob them of the power to assist others much in return.'[109] If we assume that certain genetic traits will make it possible to predict the extent to which someone will be able to make a societal contribution, does it follow that prospective parents are subject to an ethical duty to act in such a way as to maximise that potential? Or at very least to act so as to eliminate the possibility that their offspring will be so burdened by inherited disability as to be almost guaranteed to require expensive medical treatment or other support?[110]

To assess this claim, we must assess three separate premises. First, does 'society' have an interest in avoiding the birth of those with traits that will hinder their ability to assist others, or which make it likely that they will need expensive treatment or assistance? Second, can we identify, through preimplantation testing, which traits these are likely to be? And third, even if these questions can be answered in the affirmative, does this give rise to a duty upon prospective parents to make certain preimplantation choices? If each of these questions can be answered in the affirmative, then a fourth question necessarily arises concerning the relative weights of that interest and the parental interest in reproductive liberty.

Let us consider first the question of whether there can be said to be a societal interest in avoiding the birth of children who will be net 'takers from' rather than 'contributors to'

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[108] 'Loving Future People', in *Reproduction, Ethics and the law: Feminist perspectives.* Ed. Joan C Callahan (Indiana Uni Press, 1995), p.313.

[109] Ingmar Persson, 'Equality and selection for existence', *Journal of Medical Ethics* (1999); 25: 130-136, at p.131.

[110] Note that this claim is different from that considered in Section 1.2, which asserted only that the availability of PGD would give rise to a *societal belief* that prospective parents should avoid having disabled children. The claim

the common pool of material resources.[111] John A. Robertson is a renowned champion of a liberal approach to reproductive technologies, yet he has taken this possibility quite seriously:

> It may be that any additional child makes demands on societal resources, and incurs public subsidies to some extent. It may also be that only some children subsidized in this way repay those costs over their lifetime through their own contributions. ... Persons who reproduce knowing that they will depend on the welfare system or the charity of others to support their children will be imposing costs on others.[112]

It is certainly intelligible to suggest that, for those whose interests make a demand upon a finite shared pool of available resources, those interests may to an extent be set back by the presence of other individuals who will be rivals for those resources. Thus, someone affected by cystic fibrosis who may very well, in time, require a lung, heart-and-lung, or (due to the high incidence of secondary infection) kidney transplant may be said to have an interest in avoiding the birth of other CF sufferers who may, in time, become rivals for available organs.

This possibility was discussed earlier in this chapter, as a possible response to expressivist objections, and it is not one that can lightly be discounted. As I suggested earlier, finding the balance between the expressivist harms inherent in a policy of 'screening out' future similarly affected people, and the more objective harms arising from the presence of more competitors for scarce resources, is no simple task. This uncertainty as to which course of action would be the more harmful to people affected by similar conditions allowed me to propose, earlier in this chapter, that the wishes and interests of prospective parents should be accorded precedence, simply because of the possibility of ascertaining precisely where their interests lie.

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to which Purdy refers is that, whatever most people happen to believe, prospective parents *are* subject to such an ethical duty.

[111] It is, of course, the case that material resources account for only one way in which someone's life impacts on the world around them, but less tangible contributions being almost impossible to evaluate in the abstract, the present discussion must be confined to the material.

[112] John A. Robertson, *Children of Choice: Freedom and the New Reproductive Technologies*, Princeton, New Jersey, Princeton University Press, 1994, at p.77.

While different disabled individuals and groups may have different, or even diametrically opposed, interests in relation to whether similarly disabled people are born in future, the same may not be true of the non-disabled population. Expressivistic concerns, and interests in developing better treatments for the condition in question, will not be relevant to those who are rivals not for a particular resource or treatment, but rivals for resources from a larger shared pool, such as from the National Health Service, or the welfare state more generally. The care and treatment of those affected by single gene disorders is said to cost the UK state around £2 billion every year.[113] Anyone who suffers from a shortage in NHS resources, considered at the macro or meso level, might be thought to have a grievance against those parents who, deliberately or 'negligently', gave birth to a child with expensive healthcare needs. Indeed, it might be thought that anyone who either pays into that shared resource pool, or in any sense requires to take from it, might complain that the choice of (or refusal to choose by – though this itself is, of course, a sort of choice) such parents harms their interests. The taxpayer and the pensioner alike could claim to be harmed, to some extent, by such choices.

My third question will consider the possibility that such interests are too remote, too disparate and too minimal to outweigh the interest in reproductive liberty, but before turning to that, we must consider the second question. Can we, with any accuracy, identify traits through preimplantion screening that will allow us to designate embryos as likely 'givers' or 'takers'? In some cases, this will almost certainly be possible; those conditions almost universally agreed to be disastrous, such as Lesch Nyhan syndrome (considered in Chapter 3), will result in a child with expensive medical and caring needs who will never live long enough to make any sort of material contribution to the shared pool of resources.

Those conditions aside, though, what are we to say of conditions such as CF or DMD that will, predictably, affect individuals in a manner that places demands upon healthcare

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[113] *Our Inheritance, Our Future: Realising the Potential of Genetics in the NHS*, Cm. 5791, June 2003, at para. 1.8.

resources while, through physical infirmity and decreased life expectancy, limiting their ability to contribute? What of late-onset conditions such as Huntington's Disease? While there can be little doubt that exceptional individuals such as Woodie Guthrie made a positive contribution, those affected by HD might be thought to start life already owing a 'societal debt'; they will, should they live long enough for HD symptoms to manifest themselves phenotypically, inevitably require a substantial investment of resources to provide 24-hour care and very possibly medical treatment for attendant complications such as infections.

Yet the task of calculating the net balance of an individual's life – as well as being, for many, uncomfortably callous – is inherently difficult. Those with CF or HD will certainly require substantial resource investments during certain portions of their lives, but these will be preceded by or interspersed with periods of independence and reasonably robust health. Furthermore, the portions of their lives during which they will require intensive support, treatment or assistance may be relatively brief. How is this to be weighed against those without such rare conditions, whose 'normal' life expectancies see them live for decades after retirment, as net 'takers' from the resource pool? Indeed, given the extent to which the over-sixties and over-seventies place demands upon the welfare state,[114] it may well be that, over a lifetime, someone with Amyotrophic lateral sclerosis (ALS) whose 'resource dependent period' will be brief though intense,[115] has a higher balance of contributions to, rather than demands upon, the common pool.

As noted above, for many people, such a calculation is inherently callous or dehumanising, but for those who would seek to rely on the 'societal burden' argument against the laissez faire approach, a far more sophisticated and informed analysis will be

[114] 'The NHS spent around 40% of its budget - £10 billion – on people over the age of 65 in 1998/99. In the same year social services spent nearly 50% of their budget on the over 65s, some £5.2 billion.' Department of Health, *National Service Framework for Older People*, March 2001, Chapter One, paragraph 2. Available online at http://www.dh.gov.uk/assetRoot/04/07/12/83/04071283.pdf. This is despite the fact that over-65s comprise only 16% of the UK population; National Statistics Online, available at http://www.statistics.gov.uk/cci/nugget.asp?id=949.

[115] '[T]he mean survival time with ALS is three to five years'; ALS Association website, at http://www.alsa.org/als/symptoms.cfm?CFID=175234&CFTOKEN=39766255. It should be noted that the causes of ALS are still somewhat uncertain, although it is believed that at least *some* cases are genetic in origin.

necessitated than a simple assumption that those with 'disabilities' are more burdensome, on balance, than those with 'normal' health.

The third question that must be addressed is whether, even if we concede some sort of societal interest in avoiding 'uneconomical' lives, and assume further that such lives can be identified in advance, this gives rise to an obligation on the part of prospective parents. That someone has an interest bound up with one's decision is not always enough to give rise to an ethical duty to further that interest, especially where competing interests (including one's own) must also be weighed in the balance. More specifically, the implications in recognising the existence of a reproductive 'duty to society' would, were it to be consistently applied, extend considerably beyond the area of PGD.

It is well documented that Europe faces a demographic problem arising from the coincidence of falling birth rates and increasing life expectancy,[116] such as may be thought to give rise to a non-trivial interest on the part of the present population that potential parents have more children than they are, if they follow the average, likely to do. Does this impose an ethical duty on those potential parents – who may have no desire whatever to become actual parents – to reproduce? For if it does not, then it is difficult to see how they can be thought to be subject to duty to reproduce *in a certain, particularly beneficial manner.*

Perhaps it might be argued that, while no potential parents are required to act so as to positively contribute to pool of shared resources, all may be expected to act in such a way as to avoid (or minimise the chances of) making unnecessary demands of it. On such a view, we need not think them ethically required to create *any* child in order to think them ethically required to avoid creating a seriously disabled one. Yet this rests upon an assumed all-important distinction between positive and negative obligations that was shown, in Chapter 2, to be somewhat suspect. If the interests of their fellow citizens

[116] 'The current worker-pensioner ratio in Europe has fallen to about three workers for each pensioner, and it looks set to fall to a mere three workers for every two pensioners within thirty years.' 'Work longer, have more babies', Leader column in *The Economist*, 27 September 2003.

in receiving more generous pensions is the legitimate concern of potential parents, it should not matter whether those interests are adversely affect this interest by their 'decisions to' or their 'decisions not to.' From the harm perspective, both action and inaction will have the same outcome.

I would suggest, then, that all three of the questions I have addressed pose problems for the 'irresponsible reproduction' objection to the Genetic Supermarket hypothesis. However, even were we to take the view that these questions could be answered in the affirmative, any such 'societal interest' must be shown to outweigh the interest the potential parents have in reproductive liberty. Inevitably, the business of balancing such radically different interests in any objective manner is a forlorn endeavour, but it may well be suggested that the immediate direct interest of the prospective parents in choosing what child they bring into existence weighs heavily against the relatively distant and trivial interests possessed by those whose investment in that decision amounts only to a tiny fraction of their present or future income, or to a miniscule reduction in their prospects of receiving healthcare treatment. As I suggested in Chapter 1, the outcome of reproductive decisions will have significant impacts on the future lives of the potential parents, and that gives rise to a strong pro tanto case that their choices should not lightly be interfered with. To quote Robertson again, since the 'reproductive interest is generally a strong one, only very compelling needs would justify overriding their fundamental right to procreate. Saving money and preventing offense ordinarily would not rise to the required level.'[117]

4.7 Conclusion

Unlike the suggested harms considered in Chapter 3, those I have examined here are neither discountable on empirical grounds (as with the purported harm to the discarded embryo) nor conceptually incoherent (as was the case with suggested harms to potential future people or to those children whose lives are subjectively worthwhile on balance).

[117] John Robertson, *Children of Choice*, op. cit., at p.85.

Rather, the possibility of harm accruing to existing disabled people is both real and non-trivial.

In relation to those subjective harms referred to as 'expressivistic', however, I have attempted to show that a laissez faire approach to PGD, whereby the state adopted a position of neutrality towards the selection of traits for which testing would be available, might in fact diminish rather than exacerbate the degree of harm. The current HFEA policy of allowing PGD only for the exclusion of serious genetic disorders (and now for ensuring HLA compatibility) might very well be thought to communicate the idea that lives affected by such disorders are devalued. A state of affairs wherein PGD could be selected either to eliminate or maximise the possibility of a particular condition being passed on would, I suggest, largely address such concerns.

Insofar as expressivistic concerns relate to those who feel uneasy in the face of the counterfactual speculation about what their parents *might have* done had PGD been available to them, I suggest that such lingering doubts will persist whether or not that technology is now available. Furthermore, since their present disquiet derives precisely from the lack of choice that was available to their parents, it is difficult to see how we avoid the prospect of such anguish in a new generation of disabled children by similarly denying such choices to a new generation of potential parents.

The position of neutrality I have advocated in the first part of this chapter, however, where the state neither denies nor provides access to PGD for any particular trait (with the possible exceptions of aneuploidy and those that would give rise to WTN lives), may be thought to sit uneasily with certain notions of justice. In the second part of this chapter, I have sought to demonstrate that while a Genetic Supermarket in PGD constitutes a prima facie problem for justice, it is in fact only a new manifestation of an old problem, and arguably one that is scarcely worse than the status quo.

If it is unjust for the fortunate to profit as a result of advantages that they have neither earned nor chosen, then this remains the case whether those advantages were bestowed upon them by their wealthy parents, or by the 'chromosomal lottery'. In neither event do they *deserve* their advantage, and in both cases those concerned with justice should be equally concerned with finding ways to ensure that the products of their good fortune are distributed equitably. The existence of a Genetic Supermarket will not obviate the need for such measures, but nor will it be a prerequisite of their necessity.

Chapter 5 Regulating PGD in the United Kingdom

When Robert Nozick coined the term 'Genetic Supermarket' in 1974, he was writing in an era when even IVF was undreamt of by most lay persons. The question of parents actually being able to make choices about the genetic composition of their offspring was no more than an admittedly fascinating thought experiment, firmly rooted in the realm of the hypothetical. Indeed, for the next quarter of a century, the debate remained a largely theoretical one; although the increasingly widespread availability of IVF rendered the possibility more plausible, the actual 'hard cases' that so engaged ethicists intrigued by the notion of the Genetic Supermarket did not materialise.

In the first few years of the Twenty-first Century, however, three instances have arisen in the UK where couples have sought to use PGD technology in ways which might be considered ethically and legally problematic. Although only one of those cases – that involving Shahana and Raj Hashmi[1] – actually reached the courts, all three were subject of controversial HFEA decisions and intense media scrutiny. Furthermore, although the other two couples – the Mastertons and the Whitakers – elected to not to pursue their cases through the courts, their circumstances allow for a consideration of the sorts of purposes for which real people might want to make use of the Genetic Supermarket.

Equally importantly, of course, the respective attempts of the Hashmis, Whitakers and Mastertons to use PGD provide a valuable insight into how the courts and the regulatory bodies are likely to respond to such attempts. Have the principles suggested thus far in this thesis been reflected in these decisions? To what extent have the Harm Principle and the Non-Identity Principle shaped or informed the approaches and decisions of the courts and the HFEA? And insofar as they have not been the driving principles, to what alternative principles have these decision-making bodies looked for guidance?

Starting with that of the Hashmis, this chapter will consider these applications, and the court cases, consultations and reports through which they were determined.

[1] *R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority* [2003] 3 All ER 257

5.1 Tissue typing

5.1.1 The Hashmis: Background

Zain Hashmi suffers from beta thalassaemia major, an autosomal recessive genetic disorder which causes an abnormally high rate of breakdown of red blood cells, leading in turn to severe anaemia. Sufferers require frequent blood transfusions, but such a regimen can cause iron overload and consequent organ deterioration. It was therefore considered that the only long-term solution, and certainly the only *cure* for the condition lies in correcting the genetic defect by bone marrow transplantation.[2]

Developments in the field of stem cell technology, however, have obviated the need for actual bone marrow. It has been discovered that '[c]ord blood from neonates contains substantial numbers of haemopoietic stem cells, which can be harvested at delivery, frozen, and then transplanted to patients who would not otherwise have a donor'.[3] Rather than subjecting the donor to the painful process of bone marrow retrieval in the future, then, all that would be required was a quantity of blood from his or her umbilical cord.

Those wishing to utilise this technology are still faced with the problem of finding a suitable donor, one who is Human Leukocyte Antigen (HLA) compatible. As with all transplant situations, the likelihood of finding a match among genetic relatives is higher than among the population at large, but since neither Zain's parents, nor any of his three elder siblings, were compatible, the Hashmis undertook to have another child that could act as a donor for Zain.

Their first attempt ended in unfortunate circumstances; prenatal testing revealed that the child Shahana Hashmi was carrying would be afflicted with the same condition as Zain, and she elected to have an abortion. A second pregnancy was more successful, in that the child was unaffected, but it became quickly apparent that this child was not a suitable tissue match and could therefore not provide the required

[2] Lucarelli, G., Andreani, M., Angelucci, E. 'The cure of thalassemia with bone marrow transplantation' *Bone Marrow Transplantation* (2001); 28: S11-3.
[3] Lennard, A. L., Jackson, G. H. 'Stem cell transplantation'. *British Medical Journal* (2000); 321: 433-437

transplant. This outcome was not entirely surprising; as the HFEA Ethics Committee was to explain, even among siblings, the chances were not especially favourable:

> The chances of the technique being successful (i.e. resulting in the birth of a healthy, unaffected, tissue-compatible donor) will need to be calculated separately in each case. With an autosomal recessive condition, for example, on average three-quarters of embryos created would be unaffected, although one half would be carriers. As one quarter would be HLA compatible, this gives ... a 1/16 chance of a normal HLA compatible embryo or a 3/16 chance of an unaffected HLA compatible embryo.[4]

Around this time, Mrs Hashmi discussed her problem with Dr Simon Fishel, the Director of CARE (Centres for Assisted Reproduction Limited), the 'largest single provider of in vitro fertilisation ... services in the United Kingdom'.[5] Dr Fishel was aware of a groundbreaking procedure being piloted at the Reproductive Genetics Institute ('RGI') in Chicago, and he brought this to Mrs Hashmi's attention. The procedure Dr Fishel described comprised five steps:

1. the creation by in vitro fertilisation of several embryos, using gametes from Mr and Mrs Hashmi;
2. the biopsy of a single cell from the embryos thus created;
3. the use of PGD to screen those embryos for the presence of beta thalassaemia (henceforth referred to as Phase 1 screening);
4. simultaneous screening of the embryos to ensure HLA compatibility with Zain (referred to by the court as 'tissue typing', but henceforth referred to as Phase 2 screening);
5. jettison of those embryos found either to be affected by the disease or to be HLA-incompatible with Zain.

Although, as discussed in the Introduction, PGD had already been used for the screening out of embryos that carried genetic diseases, Phase 2 screening had not been carried out in the UK before. Fishel therefore enquired of the HFEA whether a license would be granted for such a procedure.

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[4] Ethics Committee of the Human Fertilisation and Embryology Authority, (2001), *Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors*, 22 November 2001

[5] *R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority* [2003] 3 All ER 257, per Lord Phillips of Worth Matravers MR, at p259

The HFEA appears to have found this question somewhat troubling. In 1999, a Joint Working Party (JWP) of the HFEA and the Human Genetics Commission had been established to consider the extent to which, and circumstances in which, PGD should be available. When it reported in 2001, the Working Party recommended that PGD 'should only be available where there is a significant risk of a serious genetic condition being present in the embryo'.[6]

The use of PGD to ensure the birth of a suitable tissue donor had not been specifically considered in the consultation process preceding the Report, but it is clear that it was tacitly precluded by the terms of this Recommendation. While the first phase of screening, to ensure the new child would itself be free from genetic illness, would appear to fall within the terms of Recommendation 11, the second phase, to ensure compatibility with the existing child, clearly would not. Indeed, the Report went on to make this rejection of HLA typing explicit, at least until further discussion of the perceived ethical difficulties took place.[7]

This further discussion was carried out by the HFEA's Ethics Committee, a body set up by the HFEA and comprising the Authority members 'with the most relevant experience',[8] which in December 2001 published a document entitled 'Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors'.[9] These new guidelines allowed for the possibility of the use of PGD for this purpose, but such use was tightly restricted by the conditions which it attached. These conditions will be discussed in more detail later in this chapter.

The Ethics Committee's recommendation seems to have satisfied the HFEA that Dr Fishel's clinic should be granted the license, and that the Hashmis should therefore be permitted to make use of the two-phase screening technique.[10] (As will be

[6] Joint Working Group of the HFEA and Human Genetics Commission, *Outcome of the Public Consultation on Preimplantation Genetic Diagnosis*, November 2001, Recommendation 11.
[7] Ibid, at paragraph 29.
[8] Sheldon and Wilkinson, 'Hashmi and Whitaker', loc. cit., at p162.
[9] Opinion of the Ethics Committee of the Human Fertilisation and Embryology Authority, 'Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors', November 22, 2001, available at
http://www.hfea.gov.uk/PressOffice/PressReleasesbysubject/PGDandtissuetyping/Ethics%20Cttee%20PGD%20November%202001.pdf.
[10] Human Fertilisation and Embryology Authority Press Release, 13 December 2001, 'HFEA to allow tissue typing in conjunction with preimplantation genetic diagnosis'

discussed in due course, however, not all of the Ethics Committee's recommendations were taken on board by the Authority).

In contrast to many accounts of developments at the 'cutting edge' of reproductive and genetic technology,[11] the HFEA's decision in the case of Raj and Shahana Hashmi was widely welcomed, by the popular press as well as the medical profession.[12] The HFEA, it was thought, had adroitly picked a path through an ethical minefield, balancing the life of Zain Hashmi, and the reproductive freedom of his parents, against the possible ethical perils of 'designer' and 'spare-part babies'. The latter concerns were, it is widely considered, reflected in the strict guidelines on tissue typing which the Authority had published a few months prior to the decision.[13] As then-chairwoman Ruth Deech reassured the press, '[t]he authority will only approve the treatment in very rare circumstances and under strict controls'.[14]

[11] For one example among literally hundreds, consider the front page story in the *Metro* on 3 July 2003, in response to the revelation that Chicago scientist Dr Norbert Gleicher had injected male cells into female embryos in an attempt to find treatments for genetic disorders. Under the headline 'Now scientists create a he-she', the story went on to describe the breakthrough as 'the latest in a chilling series of genetic announcements', and pointed to alleged parallels with 'the work of concentration camp doctor Josef Mengele' who 'experimented on Jewish prisoners in an effort to create a master race.'

[12] 'Why Mr and Mrs Hashmi were right to choose life', *Independent on Sunday*, 24 February 2002; 'The virtue of IVF', *The Observer*, 24 February 2002

[13] Human Fertilisation and Embryology Authority, 'A Summary of the One Hundred and Thirteenth Meeting of the Human Fertilisation and Embryology Authority' on 29th November 2001, at http://www.hfea.gov.uk/aboutHFEA/archived_minutes/00028.htm

[14] Clare Dyer, 'Watchdog approves embryo selection to treat 3 year old child.' *British Medical Journal* (2002); 324: 503

5.1.2 The Select Committee on Science and Technology

In July 2002, the HFEA's decision in relation to tissue typing in circumstances like those of the Hashmis, together with Chairwoman Ruth Deech's defence of that decision, were the subjects of criticism from the House of Commons Select Committee on Science and Technology.[15] Noting that the public consultation process had not addressed the scenario that arose in the Hashmi application, and that the only consideration of this particular practice had been before the HFEA's Ethics Committee, the Select Committee took the view that

> The HFEA's decision to allow tissue typing in conjunction with preimplantation genetic diagnosis went beyond the scope of its own public consultation. It is vital that the public are taken along with decisions of such ethical importance.[16]

In response to Ruth Deech's submission that the fact that the HFEA took the decision on PGD 'protects Members of Parliament from direct involvement in that sort of thing',[17] the Select Committee retorted that 'Parliament does not need protecting and democracy is not served by unelected quangos taking decisions on behalf of Parliament.'[18] The Select Committee concluded on this issue by drawing attention to the fact that '[a] pressure group, Comment on Reproductive Ethics, is seeking judicial review in the High Court on PGD on the grounds that the 1990 Act only permits distinguishing between embryos on the basis of whether they are healthy or not or for providing treatment services to the mother', warning that '[s]hould this ultimately be successful, Parliament's intervention may be inevitable.'[19]

5.1.3 The case

The licence on question was granted on 22 February 2002, but the HFEA's policy decision to permit HLA tissue typing was by this time already the subject of a legal challenge. Josephine Quintavalle, backed by the pressure group Comment on Reproductive Ethics (CORE), sought judicial review of the HFEA's decision, on the

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[15] House of Commons Select Committee on Science and Technology, Fourth Report, 18 July 2002, at http://www.parliament.the-stationery-office.co.uk/pa/cm200102/cmselect/cmsctech/791/79103.htm
[16] Ibid, at para. 17.
[17] Ibid, at para.18.
[18] Id.
[19] Id.

grounds that it had acted *ultra vires* of the powers vested in it by the Human Fertilisation and Embryology Act 1990.

(The Quintavalle family was by this point no stranger to the English civil courts, Mrs Quintavalle's son, Bruno, having already attained prominence by challenging – initially successfully, although he ultimately lost on appeal to the House of Lords - the efficacy of the 1990 Act in prohibiting human cloning.[20] It is interesting to speculate on the extent to which the courts are likely to replace the legislature as the primary forum within which bioethical disputes will be played out.)

The basis of Mrs Quintavalle's challenge lay in the wording of the 1990 Act, and comprised four elements:

1. Section 3 of the Act prohibits the creation or use of any embryo 'except in pursuance of a licence'.[21]
2. Section 11 of the Act limits the circumstances within which the Authority may issue a licence to those set out in Schedule 2.[22]
3. Schedule 2 provides, inter alia, that a licence may only be issued if 'it appears to the Authority to be necessary or desirable for the purpose of providing treatment services'.[23]
4. The definition of 'treatment services' is in turn spelt out in Section 2(1), which provides the following definition: ' "treatment services" means medical, surgical or obstetric services provided to the public or a section of the public for the purposes of assisting women to carry children.'

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[20] *R. (on the application of Quintavalle) v Secretary of State for Health* (2002) 63 B.M.L.R. 167, (2003) 71 B.M.L.R. 209.

[21] 3. **Prohibitions in connection with embryos**
(1) No person shall
(a) bring about the creation of an embryo, or
(b) keep or use an embryo,
except in pursuance of a licence.

[22] 11. **Licences for treatment, storage and research**
(1) The Authority may grant the following and no other licences -
(a) licences under paragraph 1 of Schedule 2 of this Act authorising activities in the course of providing treatment services,
(b) licences under that Schedule authorising the storage of gametes and embryos, and
(c) licences under paragraph 3 of that Schedule authorising activities for the purposes of a project of research.

[23] Schedule 2, Paragraph 1(3).

Quintavalle's contention was that the Hashmis' intention to use IVF/PGD for tissue typing did not fall within the definition of 'providing treatment services', and therefore fell outwith that range of purposes for which the Authority could legitimately issue a licence.

The Authority responded to this challenge with two contentions of its own. Firstly, it submitted that the testing for HLA compatibility of a cell biopsed from an embryo did not constitute 'use' or 'creation' of an embryo, and therefore did not require a licence within Section 3 of the Act. While it accepted that the removal of a cell from the embryo constituted 'use of an embryo',[24] whatever was done to that cell once removed, it averred, could not be so defined.

In the event that this first submission was rejected, the Authority submitted that it was in any event within its power to grant a licence for this purpose, since tissue typing was 'at least desirable for the overall purpose of providing fertility treatment'.[25] Again, Quintavalle disputed this, maintaining that the purpose of tissue typing was not to 'assist women to carry children', but rather, 'to ensure that a child born to a particular woman would have tissue that was compatible with the tissue of a sibling.'[26]

On 20 December 2002, at the High Court, Justice Maurice Kay decided in favour of Mrs Quintavalle.[27] He rejected the Authority's contention that tissue typing did not constitute 'use of an embryo', deeming it 'inconceivable' that Parliament could have intended to exclude such a practice from regulation by the Authority.[28] Having stated that the procedure *required* a licence, he then went on hold that, contrary to the second of the Authority's submissions, the procedure *could not* be licensed, since – as Mrs Quintavalle had contended – tissue typing could not be said to be 'necessary or desirable for the purpose of assisting a woman to carry a child'.

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[24] *R (on the application of Quintavalle) v Human Fertilisation and Embryology Authority* [2003] 3 All ER 257, at p263, para.16
[25] Ibid, at para. 17.
[26] Ibid, at para. 18.
[27] [2003] 2 All ER 105.
[28] Ibid, at pp..

The Authority appealed against this decision, and was supported in that appeal by the Secretary of State for Health, who was concerned that the decision, were it to stand, could impede the use of PGD more generally, and specifically for the purpose of eliminating genetic disease.[29] The trial judge's interpretation of the relevant section as being restricted to allowing a woman to become pregnant and carry a child to term was arguably not wide enough to permit screening for genetic disorders that would not manifest themselves phenotypically until after birth.[30] Certainly, it is clear from CORE's website that their objection was not solely to tissue typing, but to PGD more generally.[31]

On appeal, counsel for the Authority dropped the first strand of its case at first instance. Carrying out the biopsy, it was conceded, clearly involved 'using' the embryo, and therefore must itself be 'for the purpose of assisting a woman to carry a child'. Since the purpose of the biopsy was to allow tissue typing, then in order for the biopsy to fall within the terms of the Act, so to must the tissue typing.[32] Both parties, therefore, now agreed that, if tissue typing were to be permitted, a licence from the Authority would required.

The Authority's case, rather, relied on a contention more central to the matter, namely, that

> the entire treatment, comprehending creation of the embryo, biopsy for PGD and tissue typing, the analysis of the cell removed by the biopsy and the implantation of the embryo, if it proved to be free of disease and a tissue match for Zain[33]

amounted to treatment 'for the purpose of assisting a woman to carry a child'. Counsel for the Authority disputed the judge of first instance's narrow interpretation of that phrase, which seemed to see 'treatment services' as 'hav[ing] as their sole object the assistance of the physical process of producing a child.'[34] Rather, a

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[29] A concern shared by the Authority itself; see [2003] 3 All ER 257, at p281, para 116.
[30] Ibid, at pp.281-282, para.116.
[31] 'PGD is purely and simply another example of modern eugenics, practised ever earlier on developing human life. ... With PGD the purpose of diagnosis is simply to identify who should be killed. Neither for the disabled baby in the womb, nor for the disabled embryo do you offer any choice but the final solution - death.' From CORE's Response to Human Fertilisation and Embryology Authority/ Advisory Committee on Genetic Testing Consultation Document on Preimplantation Genetic Diagnosis, available at http://www.corethics.org/document.asp?id=fresponse.htm&se=3&st=5
[32] [2003] 3 All ER 257, at p264, para.20.
[33] Ibid, at p264, para.20.
[34] Ibid, at para 21.

broader reading of the phrase – one which, it was contended, was closer to legislative intention – took account of the fact that, in some circumstances, allowing a woman to eliminate the possibility of genetic disease could be regarded as assisting her to carry a child, since '[w]ithout such knowledge some women who carried genetic diseases would not be prepared to have children.'[35]

Were it to be accepted that PGD for the 'screening out' of genetic disease fell within the definition, counsel for the Authority went on, it followed that the purpose for which Mrs Hashmi wished to use PGD should also be so regarded, since

> In the same way tissue typing would assist Mrs Hashmi to carry a child, for her wish to do so was conditional upon knowing that the birth of that child would be capable of saving the life and health of Zain.[36]

When challenged as to whether such a wide reading of the Act could allow PGD for the selection of *any* traits to be regarded as 'assisting', and thence the subject of a possible licence, counsel for the Authority conceded this possibility, but regarded the policing of the use of this technology to be the proper responsibility of the Authority, and not a reason to read the governing legislation restrictively.

Counsel for Mrs Quintavalle responded by reiterating his insistence that 'treatment services' should be interpreted narrowly, as referring only to measures required to overcome problems in conceiving and maintaining a pregnancy. To this, however, he added the second claim that, even if the term could be extended to include measures to screen out genetic defects, what the Hashmis sought was a step further than even this, being designed 'to reject healthy and viable embryos because they lacked some desired characteristic.'[37]

In considering the respective merits of these submissions, the Court of Appeal adopted 'a purposive construction of the statute',[38] placing considerable importance on the intent of the framers of the 1990 Act. The Master of the Rolls, Lord Phillips of Worth Matravers, was impressed by the argument from counsel for the Authority

[35] Ibid, at p.264, para. 21.
[36] Id.
[37] Ibid, at p.265, para. b.
[38] Sally Sheldon and Stephen Wilkinson, 'Hashmi and Whitaker: An Unjustifiable and Misguided Distinction?' *Medical Law Review* (2004); 12: 137-163, at p144.

to the effect that Parliament tacitly permitted screening of embryos for genetic abnormalities. Mr Pannick had pointed to 3(2)(b) of Schedule 2, which permits the licensing of embryo research activities for the purpose of 'developing methods for detecting the presence of gene or chromosome abnormalities in embryos before implantation'. If, he argued, Parliament specifically made allowance for *research* into such screening, it would be strange indeed if it intended to prohibit the screening itself. Lord Phillips found this argument persuasive.[39]

Parliamentary intent, then, had not been specifically to prohibit embryo screening; but did it follow that it had been specifically *permitted*? Did screening fall within the definition of 'assisting women to carry children'? Though admitting that his initial reaction was to agree with the trial judge, i.e. that the phrase should be interpreted narrowly as applying only to 'treatment designed to assist the physical processes from fertilisation to the birth of a child',[40] Lord Phillips eventually came to the view that screening could fall within this definition. An unwillingness to risk the birth of a child affected by a hereditary defect could, he reasoned, constitute an impediment just as surely as a physical problem, and treatment which circumvented that impediment could be regarded as being 'for the purpose of assisting women to carry children'.

Having accepted that screening for genetic disorder could fall within the terms of the Act, the next question for Lord Phillips was whether this could be extended to tissue typing. While conceding that this might be thought to amount to a step too far for the Authority, Lord Phillips was not prepared to draw a distinction between those cases of PGD that are intended to screen out genetic disease, and those designed to select other traits, such as HLA compatibility:

> My conclusion is that whether the PGD has the purpose of producing a child free from genetic defects, or of producing a child with stem cells matching a sick or dying sibling, the IVF

[39] See also the judgment of Lord Justice Mance at p.283, para. 120: "While it is theoretically possible that parliament intended to permit research into methods of detecting abnormalities, or into applications of knowledge acquired about disease, which it would be impermissible to licence for practical use unless the Act was amended, it seems improbable that it was contemplated that research, a particularly contentious matter, should be permitted into methods and applications the use of which in practice Parliament had decided to exclude."

[40] At p270, para.43

> treatment that includes the PGD constitutes 'treatment for the purpose of assisting women to bear children'.[41]

In short, these were matters which Parliament had intended for the Authority to decide, and it had acted perfectly properly in exercising this discretion in the case of the Hashmis.

Lord Justice Schiemann adopted a similar approach, drawing attention to the distinction in the Act between those activities that were prohibited altogether,[42] and those which may only be done in pursuit of a licence issued by the Authority. He further concurred with Lord Phillips that 'it was lawfully open to the Authority to come to the conclusion that [PGD] would assist some women, who would otherwise refrain from conception or abort either spontaneously or deliberately, to carry a child.'[43] In a somewhat curious phrase, he stated his view that 'paragraph 1(1)(d) is wide enough to embrace ensuring that the embryo does not suffer from a genetic defect and tissue incompatibility.'[44]

Whether an embryo may meaningfully be said to 'suffer' from tissue incompatibility is surely questionable – any suffering, it might be assumed, will be on the part of the sibling that will be denied a transplant – but again, the reasoning seems to be that, since the principal reason for the pregnancy is the creation of a donor, then the inability to ensure that the next child will be a tissue match will constitute an obstacle to the pregnancy. As such, providing such a guarantee may be regarded as 'assisting women to carry children'.

To the concern that such a ruling could open the proverbial floodgates to any choices prospective parents might want to make about their children's genetic constitution, provided such choices were stated as preconditions of their birth, Lord Schiemann was, like Lord Phillips, prepared to entrust the policing of this to the Authority:

> I point out in conclusion that Parliament did not impose upon the Authority any express obligation to sanction the grant of licences even if what was proposed was indubitably necessary for the purpose of assisting a woman to carry a child. That

[41] At p271, para.48.
[42] Including, inter alia, placing a non-human embryo in a human, or vice versa; keeping an embryo after the appearance of the primitive streak, and cell nuclear replacement.
[43] At pp.275-276, para.89.
[44] At p.276, para.96.

> seems to me to dispose of much of the force of the argument that if what has been sanctioned in principle here and licensed in one case is lawful, then licensing activities for the purpose of social selection is an unavoidable consequence. If the decision of the Authority is upheld in the present case it does not mean that parents have a right to in vitro fertilisation for social selection purposes.[45]

Finally, Lord Justice Mance also favoured an interpretation that took account of more than allowing a woman to overcome physical obstacles to initiating and maintaining a pregnancy. As well as considering the same background sources as his fellow Justices – the Warnock Report, the White Paper that preceded the 1990 Act – he sought support for his position within the terms of the Act itself. Section 13(5) of the Act, he pointed out, specifically enjoined the Authority to have regard for the welfare of the child created thereby. That being so, he found himself

> in these circumstances left in no real doubt that the concept of "medical, surgical or obstetric services .... for the purpose of assisting women to carry children" was intended to embrace not merely services to assist women physically to carry to term and give birth, but also services to assist them to give birth to children who would be normal and healthy during their lives and would in turn be able to have normal and healthy children.[46]

The requirement, then, 'is better served if the legislation is read as permitting such screening.'[47]

5.1.4 Was the Court of Appeal correct?

The Court of Appeal's decision to overturn the first instance ruling was predicated on two assumptions: first, that the definition of 'treatment services' was wide enough to encompass PGD aimed at eliminating the possibility of a child being born with a hereditary defect; and secondly, that this in turn could be extended to apply to screening for HLA compatibility. I would suggest, however, that the former assumption is built upon considerably firmer foundations than the latter.

First, the recognition by Lords Phillips and Mance that Paragraph 3(2)(b) of Schedule 2 clearly permitted the use of embryos for research into 'developing

[45] At p.276, para.98.
[46] At p.284, para.126.
[47] Para 110

methods for detecting the presence of gene or chromosome abnormalities in embryos before implantation' lends some credence to the claim that Parliament envisaged screening for such abnormalities. It is, indeed, unlikely that the framers of the Act would allow research into a procedure, but outlaw the procedure itself.

Secondly, Lord Justice Mance was surely correct to point out that the requirement in Section 13(5) that consideration be paid to the welfare of any child born as a result of treatment seems to sit uneasily with a prohibition on screening pre-implantation embryos for even serious disorders. Although, as I have argued elsewhere in this thesis,[48] the conditions that may credibly be thought to render a life worse than non-existence are both few and rare, the requirement of Section 13(5) that the welfare of the child be considered before treatment is given seems to imply that such lives can indeed exist. Given this assumption, it seems safe to assume that catastrophic genetic disorders such as those considered in Chapter 3 are likely to be among them.

Thirdly, much of the background material referred to by the Court – in particular, from the Warnock Report,[49] the White Paper that preceded the 1990 Act,[50] and the then Secretary of State Kenneth Clarke's contributions to the debate as the Bill made its way through Parliament[51] - adds weight to the contention that the intention of the Act's framers was to allow screening for hereditary abnormalities.

As Lord Phillips recognised, however, accepting that PGD for hereditary defects was permitted within the Act was only a 'stepping stone' to the destination the appellants wished to arrive at, i.e., judicial recognition that the Authority was empowered to issue a licence for tissue typing. And that second step is one that is taken on a decidedly slippier surface. Nothing in the background materials to which the Court looked, nor in the other provisions of the Act, make explicit or implicit reference to tissue typing.

What could, perhaps, be argued is that Section 13(5) requires that concern be paid to the welfare of the child born *or any other children affected* by the treatment. Juliet

[48] See, in particular, Chapter 3.
[49] At p.266, para. 27, per Lord Justice Phillips, MR.
[50] At p.267, para.31.
[51] At p.268, para.36.

Tizzard, of the Progress Educational Trust, has suggested that this might be used to draw attention to the extent to which allowing the Hashmis to use tissue typing might further the interests of Zain in being provided with a HLA compatible sibling.[52]

This subordinate clause has caused a degree of confusion among academic commentators uncertain as to what sort of situation was being envisaged when it was inserted. If a purposive interpretation of the statute is to be adopted, it may be that this was intended as a further check on the provision of treatment – treatment providers should exercise caution if other children are likely to be harmed as a result – rather than a justification for treatment that would not otherwise fall within the terms of the Act.[53] In expressing this scepticism, however, I acknowledge that some commentators on the case are convinced that s.13(5) 'explicitly requires us to take account of the welfare of the existing sick child.'[54]

Perhaps even more questionable was the Court's decision that tissue typing could fall within the definition of 'treatment for the purpose of assisting women to bear children', on the basis that, were it not permitted, Mrs Hashmi may well not have had a further child. This is questionable, first, on empirical grounds; as noted in Chapter 3, the Hashmis maintained throughout that they most assuredly *did* intend to have another child, even before they were aware of the possibility that it could serve as a donor for Zain.

Yet the intention to have *a* child did not commit the Hashmis to having *any* child. The hereditary nature of beta thalassaemia meant that any future pregnancy had a fairly high probability of producing another child affected by the condition, and the Hashmis had already demonstrated a willingness to abort such pregnancies, while the fact that the legality of their doing so was never questioned provides proof, were any

[52] 'Why is PGD for tissue typing only not allowed?', *BioNews*, No.169, Week 29/7/2002 - 4/8/2002

[53] While noting that 'subsection 13(5) gives rise to considerable levels of ambiguity', Robert G. Lee and Derek Morgan opine that 'It is difficult to interpret these provisions other than as an attempt to place a restraint on the provision of certain modes of assisted conception to certain groups or types of women or couples.' *Human Fertilisation & Embryology: Regulating the Reproductive Revolution*. London, Blackstone Press Limited, 2001, at pp.134-135.

[54] Sheldon and Wilkinson, 'Hashmi and Whitaker', loc. cit., at p158.

needed, that beta thalassaemia falls within the criteria for a lawful abortion.[55] If Mrs Hashmi were to be unlucky enough to conceive a series of similarly affected pregnancies, all of which she were to abort, this might be thought to constitute an obstacle to achieving a pregnancy.

Whether or not electing to abort a series of pregnancies could rightly be regarded as analogous to infertility, the point remains that the Hashmis could have avoided that particular possibility by utilising only the relatively uncontentious Phase 1 testing. The sole reason for Phase 2 testing, the subject of the legal challenge, was to eliminate the possibility of a non-HLA-compatible pregnancy, a condition that most assuredly would not justify an abortion in terms of Section 1(1)(d). Thus, if Mrs Hashmi, as she claimed, intended in any event to have another child, she could have done so safe in the knowledge that it would be unaffected by beta thalassaemia. Given that possibility, it becomes more difficult to regard the provision of Phase 2 testing as a form of, or even as closely analogous with, treatment for infertility.

Furthermore, it might be thought that 'treatment' carries some connotation of restoring normal functioning after, or ameliorating the effects of, some disability or disease. Walter Glannon, for example, speaks of 'treatment' as being aimed at 'avoiding harm to people and benefiting them by allowing them to realize their interest in having healthy lives.'[56] We may well speak of 'assisting', 'enabling' or 'empowering' people to overcome other obstacles to achieving what they want, but we would on the whole speak of 'treating' them only if their health was impaired.

It could, of course, be argued that Mrs Hashmi's status as a carrier of the thalassaemia with which Zain was afflicted compromised her interest in a healthy life; if this view were taken, then PGD to screen out affected embryos could perhaps be seen as 'treatment' for that disorder. However, her inability to guarantee that any child she bore would be a suitable tissue match for Zain was not the result of any

[55] Section 1(1)(d) of the Abortion Act 1967, as amended by the Human Fertilisation and Embryology Act 1990, requires that 'there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.'

[56] Walter Glannon, *Genes and Future People: Philosophical Issues in Human Genetics*, Oxford, Westview Press, 2001, at p79.

deficiency in her health, but simply the nature of genetic inheritance. To categorise Phase 2 screening as 'treatment' seems to stretch the definition beyond normal usage.

However, uncertainties about the judicial interpretation of the 1990 Act notwithstanding, it may seem that the response of both the Authority and the Court of Appeal to tissue typing might be seen as a first victory for supporters of the Genetic Supermarket. On the first occasion that an attempt was made to curtail parental choice in use of PGD, both regulatory authority and judiciary have supported that choice. However, a closer examination of the Authority's reasoning, the conditions and caveats with which it sought to delimit this decision, and perhaps most tellingly, the contrasting approach it adopted when a similar case appeared before it a short time later, suggest that the Hashmi decision is far from the first step on the road to Nozick's ideal.

5.1.5 Conditions 1: Last resorts and necessary evils

The first two of the conditions which the Ethics Committee recommended, and the HFEA subsequently accepted, require that 'all other possibilities of treatment and sources of tissue for the affected child should have been explored'[57] and that the use of HLA typing should be limited to 'severe or life-threatening' cases.[58] In short, the HFEA requires that this technology be utilised only in cases of direst need, and even then, only as a last resort. In so doing, it might be thought that the HFEA is making a statement about the pro tanto wrongness of the technology. If, after all, there was nothing inherently wrong in the practice, there would be no need to find such compelling justification for its use; absent any ethical objection to PGD-HLA, the fact that prospective parents *wanted* to use the technology would be reason enough to permit it (although it does not, of course, necessarily follow that the NHS should fund whimsical uses).

What, then, might the Ethics Committee – and ultimately the Authority, which accepted its recommendations on these points – regard as being ethically problematic about using PGD for tissue-typing? And is it reasonable to conclude that these

[57] 'Ethical issues in the creation and selection of preimplantation embryos to produce tissue donors', November 22, 2001, at para. 3.12.
[58] Ibid, at para. 3.13.

concerns were more adequately addressed when the conditions listed are met? At the outset of its consideration, the Committee identified three questions which it hoped would guide it in framing its recommendations:

- Is PGD with HLA typing compatible with the 'welfare of the unborn child'?
- Is licensing PGD with HLA typing compatible with the public good?
- Can morally significant criteria be found to demarcate 'acceptable' and 'unacceptable' reasons for the conception and selection of embryos?

The last of these three questions might be thought to presuppose the answers to the first two, in that no such demarcation would be necessary unless there actually existed unacceptable reasons. It seems, therefore, that the question of the pro tanto wrongness of PGD/HLA rests in the first instance on its likely impact on this question of welfare, and in the second on the likely impact on the public good.

To a significant extent, the first of these questions is inextricably tied to the conclusions to Chapter 3; any harms resulting from the child's unorthodox origins must be viewed as the unavoidable costs of the child's coming to exist at all. That being so, and assuming that existence can be predicted to bring many more positives than negatives for the child (an especially likely state of affairs given the lengths that parents such as the Hashmis and Whitakers are likely to go for the benefit of their existing children), it follows that for the 'welfare' concern to count against allowing PGD/HLA, there must be some very substantial risk of very significant harm to the resulting child.

5.1.6 Welfare of the unborn child

In considering the welfare of the future child, the Ethics Committee considered both a fairly traditional formulation of the 'welfare principle', asking 'whether the outcome of the technique adversely shifts the balance of benefit and harm', (Para. 2.14) together with a more unusual formulation considered in the next section. The first, and more straightforward, of these conceptions of welfare asks whether the donor child will experience a balance of benefit over harm as a result of the technique in question. Such concern may seem entirely valid in this context. Is the

use of a child as a 'walking medicine chest'[59] not a clear example of harm to that child?

It is certainly the case that, while UK law allows parents to consent to medical treatment on behalf of their precompetent children, it does not allow them carte blanche in volunteering them for non-beneficial surgery. Rather, the overriding principle with regard to consent exercised for a child is the best interests of the child him- or herself. Can the decision of the Hashmis credibly be thought to satisfy this criterion?

In attempting to answer this question, it is essential to clarify which of the Hashmis' decisions we are scrutinising: the decision to create *a* child, the decision to screen the embryos, the decision to implant *a particular* embryo or the later decision to consent to retrieval of umbilical blood. With regard to the first decision, it may validly be asked whether it is legally necessary, or indeed even *possible*, for the decision to be based on the best interests of the child. Given that, at the time of the decision, the child in question has only a hypothetical existence, it cannot possess any sort of interests, far less best interests. How, then, can its 'best interests' inform the decisions?

It might be thought that this requirement relates to the likely foreseeable interests that the child will possess if it is brought into existence. Should not such interests be taken into account in deciding whether to create the child? Two responses might be thought to cast doubt on this requirement. First, we might ask why it should be incumbent on the prospective parents to give priority to the hypothetical interests of a future child, over the actual interests of their existing children. The decision to have another child might have a profound effect, positive (as in Zain Hashmi's case) or negative (as in the case where the parents already barely possess enough resources to provide for the children they have), on the existing children. Is it not appropriate that any future reproductive decisions take account of such impacts? Indeed, as mentioned above, Section 13(5) of the 1990 Act specifically requires that any

[59] A term employed by an anonymous reviewer of an article I submitted on this topic.

decision to provide access to reproductive technologies take account of precisely this.

Furthermore, as Sheldon and Wilkinson point out, the 1990 Act apparently does not require the best interests of the future child to be the paramount consideration but merely that account be taken of the welfare of such a child;[60] the juxtaposition of this requirement with the reference to 'any other child who may be affected by the birth' may be thought to suggest that the welfare of the created child is but one of, potentially, several parties whose interests should be of relevance to the decision.

Could the best interests requirement be satisfied by the decision to use PGD for the purposes of ensuring (or maximising the likelihood of) an HLA-compatible child? Again, this requirement would find itself embroiled in some complex metaphysical speculation. Given that the effect of PGD is to inform a decision as to which of several 'candidate embryos' to implant, for the 'rejected' embryos, the effect will be (as discussed in Chapter 3) to ensure that they never develop interests at all. To apply the best interests test to the latter group is all but meaningless.

While the selected embryo or embryos possess no interests, the children they will (hopefully) become will be interest-bearers. Does it therefore make sense to require that PGD satisfies a test of their (prospective) best interests? The difficulty here is that if we make it a prerequisite of any procedure carried out on an embryo that it benefit that embryo, or the child it will become, then that must apply equally to the act of *implanting* that embryo. How can implantation be said to be in the future child's best interests? The only interest that can conceivably be furthered thereby is some notional 'interest in becoming the sort of being that possesses interests', a metaphysically awkward construction, but one necessary to circumvent the requirement that implantation satisfies the best interests test.

Assuming, for the present, that we can say that their best interests have been furthered by a choice that led to them possessing any interests at all, then this must apply not only to implantation, but also to the use of PGD to ensure that they, and not

[60] Sheldon and Wilkinson, 'Hashmi and Whitaker', loc. cit., at p158.

one of the other candidate embryos, was selected for implantation. (Indeed, we may need to take this a step back and note that the real precondition of their existence was the use of IVF rather than natural conception, a course of events that only unfolded – in the case of fertile couples like the Hashmis - because of the availability of PGD.)

If implantation satisfies the best interests test, then so too, I suggest, does PGD. Alternatively, we may prefer the view that sees neither satisfying that test (since it cannot, we might think, be in a being's best interests merely to allow it to develop interests), but which sees the best interests test as being inappropriate for and inapplicable to preimplantation decisions. This, I would suggest, is the more plausible view. After all, the 1990 Act allows for the possibility of non-beneficial – indeed, destructive - research on embryos up to fourteen days,[61] a practice that would clearly fail any conception of a best interests test.

What, then, of the last of the parents' decisions, the decision to consent to the child acting as a tissue donor? Should that, at least, not be required to be a decision positively in the interests of the child herself? In the Hashmi case, however, there was no prospect of intrusive surgical intervention to harvest the required tissue, but rather, as explained previously, to retrieve it from the discarded umbilicus.[62] Hence, the necessity to satisfy the best interests test may, it might be thought, be irrelevant.[63]

The same could not, of course, be said of an attempt to harvest, for example, bone marrow from the child. Such donation could only be justified if it could be shown to be in the child's own best interests. *Re Y (mental incapacity: bone marrow transplant)*[64] demonstrated how this requirement can be met in the case of

[61] Human Fertilisation and Embryology Act 1990, s.3.
[62] This has been disputed by CORE, whose website proclaims that 'Dr Fishel reiterated at a recent public debate against CORE that it is indeed blood [sic] marrow which they intend to harvest, rather than the placental and cord blood which is usually referred to.' Press Release, 'Tissue-Typing Hearing Tomorrow', available at http://www.corethics.org/document.asp?id=CPR310303.htm&se=2&st=4
[63] The question of whether the child might have some sort of property interest in its own tissue or cells is, of course, a separate question, and one that has never, to my knowledge, been definitively answered in UK law. See, however, *Moore v Regents of the University of California* (1988) 249 Cal Rptr 494 (Cal CA) for an example of how such a claim has failed in another jurisdiction.
[64] [1997] Fam 110, (1996) 35 BMLR 111

incompetent adults, but no analogous case law exists with regard to precompetent children.[65]

However, assuming similar logic were applied, it seems that tissue donation from a child that was required to save a family member could conceivably be justified where the child enjoyed a close relationship with that relative,[66] and where the tissue required was regenerable (blood or bone marrow). Indeed, Sheldon and Wilkinson have suggested that a more prospective approach could be adopted to best interests, according to which 'it could surely be argued that A [the selected sibling] would benefit from B's [the existing child] company and may well derive pleasure from knowing that she has saved B's life',[67] while the authors of another article on tissue typing have gone so far as to suggest that 'parents who want to have another child anyway, have an obligation to try this last possibility of saving their sick child.'[68]

In any event, the decision as to whether the retrieval of tissue and subsequent transplant should take place would be determined at a later time, by weighing up the harms and risks and benefits attendant to the donation, and would be likely to require judicial approval. There is no question that the procedure would go ahead merely on the parents' say-so. It might be thought, then, that the interests of the child, once born, will adequately be protected by the courts, a fact that the HFEA seemed to acknowledge.[69] Certainly, the prospect of a court deciding whether the bone marrow harvest could be in the child's interests seems a more plausible and proportionate mechanism for safeguarding the child's interests than the intervention of the HFEA to prevent it ever being born.

What, then, of the possible emotional and psychological burdens that may be experienced by a child who grows up knowing that it was created for such a purpose?

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[65] Though Sheldon and Wilkinson seem convinced that a UK court would apply the same principles were the potential donor a precompetent child rather than an incompetent adult; see 'Hashmi and Whitaker', loc. cit., at pp. 160-161.

[66] Or even, as in the *Re Y* case, with another person who would be adversely affected by their failure to donate.

[67] Sheldon and Wilkinson, 'Hashmi and Whitaker', loc. cit., at p151

[68] Pennings, G., Schots, R. and Liebaers, I. 'Ethical considerations on preimplantation genetic diagnosis for HLA typing to match a future child as a donor of haematopoietic stem cells to a sibling' *Human Reproduction* (2002); 17(3): 534-538, at p536.

[69] Human Fertilisation and Embryology Authority, Press Release, 13 December 2001, 'HFEA to allow tissue typing in conjunction with preimplantation genetic diagnosis'

That their relationship with the parents who conceived them for that reason, or with the sibling they saved, will be adversely affected? Certainly, concerns have been expressed about the possibility of 'damage to his [the new child's] self worth',[70] while Paul Tully of the Society for the Protection of the Unborn Child has rhetorically asked 'How will this child feel knowing that he or she was selected from a group of embryos just to serve as a tissue donor to a sibling?'[71]

Such possible objections begin to look less compelling, of course, when we recall the nature of the alternative for the child in question. Because, as explained in Chapter 3, for this particular child, the alternative to being born as a tissue donor is not to be born into a more conventional family setting, but rather, *not to be born at all.* Once this is accepted, then it becomes difficult to conclude that the child created as a tissue donor is harmed by those decisions upon which its very existence is dependent. Unless we foresee that its life is likely to be so unremittingly awful that existence itself will be a burden, we must conclude that it is better off (or at least no worse off) being born into these unusual circumstances than never being born at all. There may well, as I have conceded throughout this thesis, be conditions and circumstances so subjectively unpleasant for those affected as to be worse than non-existence. It is difficult, I submit, to imagine that being born in the hope that your life will help save the life of a sibling would constitute such a circumstance.

Furthermore, if our concern is with the possibility of psychological harm to the future child, we must consider the possibility that a family deprived of the use of tissue-typing, might attempt a normal pregnancy in the hope that the resulting child will be HLA compatible with the existing child. Given the low probability that any resulting child will be both unaffected and a tissue match, we should consider what unique psychological burdens will be placed on such a child. If it is harmful to begin life knowing that one was conceived as a saviour, how much harder might it be to know that one was conceived as a saviour and 'failed' in this role, however illogical the attribution of blame for such an unchosen quality as HLA compatibility?

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[70] Richard Nicholson, 'We are some way down a slippery slope', *The Guardian*, 20 June 2003.
[71] 'The Painful Dilemma Over Babies by Design', *The Telegraph*, 3 August 2002.

While there is no legal mechanism available to scrutinise the motives nor to control the actions of parents who choose to entrust the creation of a 'saviour sibling' to the reproductive lottery in this way, the possibility that desperation would drive them to attempt this should, it might be thought, be borne in mind before the tissue typing route is blocked by those who profess concern for the welfare of 'the child' as their concern.

5.1.7 Treating the child as an end in itself

Having identified a fairly traditional conception of the welfare of the resultant child as one of its primary concerns, the Ethics Committee went on to elaborate that 'positive consideration of the welfare of the child requires respect for beings as ends and that the putative child be treated not simply as a means to a further end but also as an "end in itself."'[72] The Kantian imperative that all humans should be treated as ends in themselves is one that commands widespread adherence,[73] and it is perhaps understandable that the Committee would wish to conduct its deliberations in that light.

Whether failing to respect the new child as an end in itself actually constitutes a harm to that child, or whether it is better viewed as a violation of some wholly separate ethical principle is a more complex question. However, since the Committee clearly took the former view (although it neither explains nor justifies this contentious synthesis of the Kantian imperative and the principle of non-maleficence), it is worthwhile examining the claim that the Hashmis would indeed be treating the donor child as a means and not an end, and would thereby be harming it.

What does it mean to treat someone as a means and not as an end? As Beauchamp and Childress point out, this ethical rule is often misinterpreted as meaning simply that it is objectionable to use someone as a means to furthering one's own objectives.[74] As they explain, this could not be so without casting ethical opprobrium on every transaction between customer and vendor, employer and employee, client and service provider; quite simply, when I hire a plumber to

[72] At para 2.9
[73] See, most notably, Alan Donagan's *The Theory of Morality*, Chicago, University of Chicago Press, 1977
[74] Beauchamp and Childress, *Principles of Biomedical Ethics*, (Fifth Edition), Oxford, oxford University Press, 2001, at p351.

unblock my sink, or when I buy a newspaper from my local newsagent, I am treating them as means to my desired ends, i.e., having a sink that drains properly and reading the day's newspaper. If other means were available to attain that same objective - if non-sentient robots and vending machines were able to carry out the same tasks – I would be equally satisfied.

Since, as Beauchamp and Childress write, even Kant would not have regarded such transactions as intrinsically unethical,[75] there must be more to the Kantian imperative than merely treating other people as a means to my own ends. This extra element is encapsulated in the 'merely' element of the imperative, i.e., the proscription of treating them '*merely* or *exclusively* as a means'[76] and not *also* as an end in themselves. That is to say, there is nothing objectionable *per se* in using someone as a means, provided I do not lose sight of the fact that s/he is also an end in him/herself.

There is an obvious sense in which this imperative arises naturally from a harm-based approach; a principle that regards harms and interests as being of paramount ethical importance would introduce an unsustainable element of arbitrariness were it to hold that only *some* harms and interests were to be considered, or that some were, without good reason, to be accorded greater weight than others. In that basic sense, it would be untenable to allow the Hashmis to use the new child as a means to furthering their own, or Zain's, interests without taking into account any interests of its own which might be affected as a consequence. As discussed in the previous section, any such interests as may be attributed to the embryonic Hashmi child would relate to the sort of life it might reasonably be expected to enjoy (or endure) once it attained even rudimentary sentience. Those deselected embryos which will never attain sentience will simply never develop interests of any kind, never attain the capacity to be harmed; to speak of their being used as means and not ends is meaningless in a context where taking account of their interests is impossible.

As an adjunct to the harm-based approach, this notion of the means-ends rule perhaps serves as a useful reminder that no-one can be excluded from the calculation

[75] Id.
[76] Id.

without due cause, but that apart, it adds little to the basic approach. There are, however, other interpretations of the imperative that, while fitting less readily within the harm-based approach, are still worthy of investigation if we are to understand the reasoning of the Ethics Committee and, ultimately, of the Authority.

Alan Donagan is a leading contemporary adherent to and interpreter of Kantian ethics. For him

> Kant's formula of the fundamental principle may be restated in a form more like that of the spiritual commandment that is its original: *Act always so that you respect every human being, yourself or another, as being a rational creature.*[77]

Before examining what Donagan understands this to involve, it is perhaps worth clarifying that the imperative to respect a being as a rational creature is, for him, in no way dependent upon its being capable of rational thought. Rather, any genetically human organism is, by virtue of its species membership, entitled to respect as a rational creature, regardless of its state of cerebral development.[78] This being so, then, following a Donaganian interpretation of Kant's imperative, the Ethics Committee would have been conceptually correct to regard the embryonic Hashmi child as the sort of being that must be shown 'respect ... as a rational creature'.

What sort of duties, then, are owed to a being by virtue of its status as a rational creature? Much of Donagan's book is given over to a discussion of this question, and he identifies various 'precepts' that derive from the core imperative. He maintains, for example, that 'it is impermissible for anybody at will to use force upon another',[79] a precept that itself gives rise to derivative precepts prohibiting killing, inflicting bodily injury or holding another in slavery;[80] that '[i]t is impermissible not to promote the well-being of others by actions in themselves permissible';[81] that it is impermissible to lie;[82] and that there exists a duty (subject, as are almost all of these 'first-order precepts', to certain exceptions) to obey the law.[83]

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[77] Donagan, *The Theory of Morality*, op. cit., at p65.
[78] Ibid, at p83
[79] Ibid, at p82
[80] Ibid, at p83
[81] Id.
[82] 'it is impermissible for anybody, in conditions of free communication between responsible persons, to express an opinion he does not hold'; ibid, at p88
[83] Ibid, at p109

One striking aspect of these precepts is that they seem to give rise to a more obvious case *in favour of* HLA-typing in cases like those of the Hashmis and Whitakers than they support the contrary position. For while Donagan has nothing to say about the sort of scenario about which the Committee were asked to deliberate, the precept that imposes a positive duty of beneficence - '[i]t is impermissible not to promote the well-being of others by actions in themselves permissible' – gives arise to a pro tanto obligation to rescue Zain and Charlie. Of course, the caveat 'by actions in themselves permissible' prevents us from leaping too readily to this conclusion. But nonetheless, a first reading of Donagan's precepts seems to see the scales tilt in favour not only of allowing HLA-typing in life-or-death cases such as those under consideration, but perhaps in cases of less serious illness too; the precept, after all, does not stop at imposing a duty to save life, but rather speaks of 'promot[ing] the well-being of others'.

The question that remains is whether the actions in question are 'in themselves permissible'. It is impossible to advance a definitive answer to this without attempting a fuller study of deontological ethics, a task beyond the remit of this thesis. However, on an admittedly superficial reading, it is not obvious that HLA-typing would contravene the duty to respect the new child as an end in itself in any of the ways specifically identified by Donagan. The new child would certainly not be killed, exposed to bodily harm or enslaved. As discussed above, the positive duty to promote its interests is problematic in a context where the future child does not presently possess any interests, and there is certainly no obvious sense in which such a possibility exists but is being neglected. And duties in relation to truthfulness, honouring contracts, and obeying the law are irrelevant in this context.

What the Kantian imperative seems to require, then – at least as Donagan interprets it – is that the well-being of Zain and Charlie should be promoted unless it can be demonstrated that some other aspect of the duty – presumably as owed to the new child - is being violated. It is for scholars of Kant, of Donagan and of such duty-based ethics more generally to ascertain whether any such competing obligation exists and, if so, whether it can outweigh what Donagan clearly recognises as a duty to Zain and Charlie. For the purposes of this chapter, it is sufficient to note that it is

being no means uncontroversial or obvious that this ethical obligation to which the Ethics Committee attached such weight, namely to respect all humans as ends in themselves and as rational beings, weighs *against* HLA-typing, either in life-or-death cases or in cases where it is only well-being rather than life itself that is at stake. Indeed, it may even be that this obligation – contrary to the Ethics Committee's apparent assumption - pulls in the opposite direction.

A similar approach to the Kantian imperative has been advanced by Walter Glannon, this time in relation to the possibility of reproductive human cloning. Glannon invites us to imagine a (far from implausible) scenario wherein

> the parents of a recently deceased or dying child want to clone an individual who is genetically identical to that child and thus "replace" it to compensate for their loss or else carry on the family line.[84]

Glannon acknowledges that, if 'the sole intent of the parents is replacement or compensation, then the cloned individual would be treated solely as a means,' and that this 'would deny the intrinsic dignity and worth one possesses in virtue of the fact that one is a human agent with the capacity for reason.'[85] However, for Glannon, the motives with which the clone was created would be less important than the manner in which it is treated throughout its life:

> if the clone were loved and treated with the dignity and respect commanded by its intrinsic worth, then cloning might be morally justifiable on Kantian grounds. Although the intention to clone the child suggests that he or she would be treated instrumentally, the fact that the child is treated as a unique individual once she exists is enough to dispel any moral qualms about the parent's behavior.[86]

In short, 'how one is treated by others over the course of one's life is more morally significant than the reasons for causing one to exist.'[87]

Yet even if this is an erroneous interpretation of the duty, and HLA-typing presents greater difficulties for the duty to respect the new child as an end in itself than has been recognised here, it is by no means clear that the recommendations at which the

[84] Walter Glannon *Genes and Future People: Philosophical Issues in Human Genetics*, Oxford, Westview Press, 2001, at p118.
[85] Id. See also Pennings, Schots and Liebaers, 'Ethical considerations ...', loc. cit.
[86] Id.
[87] Ibid, at p120.

Committee arrived would follow from this. For if it is felt that 'being born to be a donor' is incompatible with being treated as an end in oneself, then it is difficult to see how this is so only when the anticipated recipient is a parent, but not a sibling. In neither case is the prospective child able to consent to the donation, nor of course to its creation. In both cases the decision involves consideration for a party other than the putative child itself. In both scenarios, in other words, the donor child is being created at least partly as a means to some other end. The next section will consider this most perplexing of restrictions.

5.1.8 Conditions 2: The parental exception

The fact that the Committee had wandered into areas of ethical confusion, and perhaps departed from its original remit, became clearest when it came to consider the possibility of utilising this technology to provide a tissue donation to a parent. Among its final recommendations, it proposed that 'because it [the Committee] favours a principle of qualified parental decision-making with respect to the use of the technique **the technique should not be available where the intended tissue recipient is a parent.**'[88] No further justification is offered for such a condition in this paragraph, and it is necessary to search the remainder of the document in some depth to locate some indication of the Committee's reasoning.

Paragraph 2.21 concluded with the claim that 'it appears *prima facie* to be morally less acceptable than selecting an embryo to provide tissue to treat a sibling, as it seems to replace concern with another with concern for oneself.' There are several observations that could be made regarding this assertion. Firstly, it may be seen to conflate that which is morally *acceptable* with that which is morally *commendable*. Undertaking a physically, emotionally and perhaps financially demanding process such as IVF and pregnancy in order to save the life of another may perhaps scale heights of altruism and selflessness greater than undertaking these burdens to save one's own life. But that is not to say that the latter course of action is morally unacceptable. To make out the case for moral unacceptability, the Committee would need to have demonstrated some aspect of the treatment that contravened some ethical principle.

[88] Paragraph 3.15, original emphasis.

Secondly, the Committee's assessment perhaps overlooks the contribution and sacrifice of the other parent. If, for example, it had been the father who suffered from a debilitating and life-threatening condition requiring stem cell transfusion, and if the couple had undergone the same procedure in attempt to find a suitable donor, would the requisite element of sacrifice and altruism not have been displayed in the mother's willingness to go through ova retrieval, embryo implantation, pregnancy and labour to save her husband?

The Committee commenced its enquiry by identifying consequentialism and deontology as the ethical principles that would guide it, but seems at this point to have slid, perhaps unwittingly, into an adherence to some kind of extreme version of virtue ethics, a position that sees only acts of supreme and selfless sacrifice as being acceptable. Yet even on those somewhat idiosyncratic terms, it is not at all clear that applying this technique to benefit a parent should not be acceptable.

Neither the 1990 Act nor the common law require parents to have wholly or primarily non-selfish motives when they act on behalf of their children. The parent whose selfish decision happens to coincide with his child's interests will not have his motives scrutinised for any hint of self-interest. Why, we might ask, should such an unfeasibly high standard be set for prospective parents seeking to use PGD-HLA?

Indeed, it might also be asked whether it is not invariably the case that, by the very fact of its conception and birth, a child is serving as a means to some other end? It is perhaps unlikely that any pregnancies are commenced wholly or predominantly out of beneficence towards the future child. Couples or individuals have children for a wide variety of reasons, ranging from the fulfilment of long-harboured life plans to unwelcome accidents, via myriad psychologically complicated motivations involving self-fulfilment, tradition, peer expectation, strengthening ailing relationships and a – perhaps subconscious – quest for some sort of genetic immortality. As Julian Savulescu has said:

> Parents have many desires related to their children: perhaps to have a companion, to have a friend to the first child, or to hold a marriage together. It is unlikely that any parent ever desires a child solely as an end in itself. ... Provided that parents love

> their child as an end in itself, there is no problem with the child's life also fulfilling some of the parents' desires for their own lives.[89]

It is also entirely common to hear parents citing a desire for companionship for an existing child as a reason.[90]

Whatever the precise reasoning, however, the fact that a couple *want* to be genetic parents is a selfish, or at best a mixed, motive, just as surely as the fact that one of them needs a donation of stem cells. It may be that in other times and in other societies, couples greeted the news of pregnancy with a stoical acceptance that they were fulfilling an unhappy duty, but it would be difficult to see this as a preferable state of affairs to that wherein the forthcoming birth of a child is seen as a joyous event for all concerned. For the most part, we want parents to satisfy their own wants and ambitions when bringing a child into the world. Of course, if these wants and ambitions were likely to harm the child once it is in existence – if the child was wanted as a slave or a sacrifice, for example - that may be problematic. But the mere fact that the creation of a life symbiotically benefits the parents is not only accepted, but is for the most part expected and welcomed.

On the restrictive interpretation of the harm-based approach that sees only the frustration of experiential interests (present or future) as justification for prohibition, what the Hashmis sought to do was unproblematic, for precisely the reasons identified in Chapter 3. But even on a wider interpretation, that views violations of critical interests such as 'being treated as an end in oneself and not merely a means' as harms, it is far from clear that the putative Hashmi child would be harmed by the means and motives according to which it was created; provided it is treated with respect, dignity and compassion once it is born, the categorical imperative is satisfied in its regard. Furthermore, I submit, this would be so whether the intended recipient of the transplant is a sibling, a parent, or any other third party.

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[89] Julian Savulescu, 'Sex selection: the case for', *Medical Journal of Australia* (1999); 171(7): 373-375, at p373.

[90] See, for example, Pennings, Schots and Liebaers, 'Ethical considerations…', loc.cit., and Sheldon and Wilkinson, 'Hashmi and Whitaker', loc. cit., at p147.

Whether the parents are motivated by altruistic concern for other children, or selfish concern for their own health, they are nonetheless viewing the new child as a means to some other end. But provided they do not view it, and more importantly do not treat it, *only* as a means, they have not violated its interest in being treated with the respect due.

5.1.9 The Whitaker case: an arbitrary distinction?

The Quintavalle challenge, then, demonstrated that the Court of Appeal was content to entrust to the HFEA the responsibility for ensuring that PGD is used only in 'appropriate' circumstances. The manner in which this task is being carried out has, I submit, been cast into doubt by the apparent ethical confusion underlying the conditions attached to the decision about HLA tissue typing. Even greater reason for dissatisfaction lies in the Authority's handling of the next application for a licence to carry out tissue typing.

Charlie Whitaker suffered from Diamond Blackfan Anaemia (DBA), a rare blood disorder requiring day-long blood transfusions. In that the condition is painful, debilitating and impossible to cure without transfusion, it is analogous to Zain Hashmi's thalassaemia. The distinction, upon which the HFEA placed so much reliance, is that DBA is rarely a hereditary condition; indeed, tests of Michelle and Jayson Whitaker revealed that they were not carriers, and that Charlie's condition was attributable to a spontaneous mutation.

As already noted, the Joint Working Party's Recommendation 11 restricted PGD to cases where the embryo being screened was itself at significant risk of developing a particular genetic condition. While the future Hashmi child satisfied this criterion – both Shahana and Raj Hashmi being asymptomatic carriers - any future child the Whitakers may have would be at no greater than average risk of developing DBA. The terms of the Recommendation, therefore, would not be satisfied in the latter case.

However, the HFEA Ethics Committee, charged specifically with the role of considering the ethics of HLA tissue-typing, reached an entirely different conclusion. Paragraph 3.14 of the Committee's Report addressed precisely the scenario in which

the Whitakers found themselves, and recommended that PGD should be available in those circumstances. In announcing in August 2002 that the Whitakers would be denied access to PGD for tissue-typing only,[91] the HFEA acted against the recommendation of its own Ethics Committee in this matter. While it is of course free to do so, it is difficult to discern what ethical or legal basis the HFEA was relying on when it made this decision.

5.1.10 The ethical approach

The Minutes of the first HFEA meeting after the Ethics Committee's Report contain only a fairly cursory discussion of the issue:

> Members felt that to allow PGD for tissue typing alone would run contrary to the requirements of the welfare of the child assessment. Therefore, it was agreed that tissue typing using PGD should only be offered where PGD was already necessary to avoid the passing on of a serious genetic disorder.[92]

As discussed earlier, the Ethics Committee had in fact identified the 'putative child's actual moral, psychological, social and physical welfare' as an issue of great significance.[93] Its Report considered both a fairly traditional formulation of the 'welfare principle', asking 'whether the outcome of the technique adversely shifts the balance of benefit and harm',[94] together with a more unusual formulation where the Committee considered the proposition that:

> It could be suggested that positive consideration of the welfare of the child requires respect for beings as ends and that the putative child be treated not merely as a means to a further end but also as an "end in itself".[95]

It is unclear which of these concepts of 'welfare' the HFEA felt to be compromised by the Whitakers' application, though not by the Hashmis'. The first version, concerned with the prospect of harm to the future child, seems to be answerable in terms of the Non-Identity Principle in exactly the same manner as in the Hashmi

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[91] HFEA, Press Release, 'HFEA confirms that HLA tissue typing may only take place when preimplantation genetic diagnosis is required to avoid a serious genetic disorder', 1 August 2002, available at http://www.hfea.gov.uk/PressOffice/Archive/43573563

[92] Human Fertilisation and Embryology Authority, *A Summary of the One Hundred and Thirteenth Meeting of the Human Fertilisation and Embryology Authority on 29th November 2001*, at http://www.hfea.gov.uk/aboutHFEA/archived_minutes/00028.htm

[93] Ethics Committee of the Human Fertilisation and Embryology Authority, *Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors*, 22 November 2001, at paragraph 3.2

[94] Ibid, at paragraph 2.14

[95] Ibid, at paragraph 2.9

scenario. Unless we can predict with confidence that either child will suffer a net balance of harms over benefits as a result of its existence, it is impossible to conclude that the very fact of its creation constitutes a harm to it.

Had the HFEA contended that the Whitakers would be likely to neglect or abuse the new child, regarding it literally as an instrument to save Charlie's life, to be tossed aside when that end was attained, then there may have been a case to answer (although the option of adoption – a very real possibility when the child's plight was inevitably trumpeted by the nation's media - would cast into doubt whether even those circumstances would render the new child's birth contrary to its interests). As far as can be ascertained from the Minutes of the November meeting, however, the HFEA at no point seriously considered the possibility that the new child would be treated in a manner likely to give rise to such concerns.

The only indication of the thinking that led the HFEA to conclude that the future child's welfare would be compromised lies in the Minutes' brief reference to 'the psychological burden that may be placed on a child who was an "engineered" match as opposed to a 'natural' match.'[96] The terminology used here might be considered imprecise and unfortunate. The Whitakers did not seek to alter the genetic makeup of their future child, as the term 'engineered' is ordinarily thought to denote. If the distinction the HFEA sought to address was between a 'selected' match as opposed to a 'randomly occurring' match, then it is not apparent how the former child would be at a disadvantage. In both cases, there will be an expectation that the child will act as a donor.

Similarly, the second of the Ethics Committee's conceptions of 'welfare' seems ill-suited to distinguish between the Hashmis' case and that of the Whitakers. The concern that the putative child be considered 'not merely as a means to a further end but also as an "end in itself"' requires that we regard the new child as an end in itself, taking account of its interests and rights, and not merely as an instrument of someone else's welfare. As discussed earlier in this chapter, such a principle may – although by no means uncontroversially – be accommodated within a consideration of the

[96] *A Summary of the One Hundred and Thirteenth Meeting of the Human Fertilisation and Embryology Authority*, op. cit.

welfare of the future child. However, as explained above, it is by no means clear that the creation of a child to serve as a donor violates this principle – provided that child is treated with the dignity and respect due to an individual, then it has not been treated solely as a means.

Furthermore, it is far from clear how it serves to distinguish the two cases. Both families sought to have a new child, and to use PGD to select that child, at least partly for the good of an existing child. Even if we were to accept that 'first phase' PGD, for disease screening, was in the interests of that future child (a conclusion that poses certain philosophical difficulties), it is surely the case that in both scenarios, the use of 'second phase' screening, for HLA tissue-typing, was sought exclusively for the benefit of another party. If the HFEA's concern is with preventing embryos being screened wholly for the benefit of someone else, then it is difficult to see how it was any more justified for the Hashmis than for the Whitakers.

5.1.11 Summary

The Court of Appeal's decision in the *Quintavalle* case, and in particular its recognition that non-pathological factors could be considered as suitable matters for 'treatment' in terms of the 1990 Act, could be seen to have lent a wide margin of discretion to the HFEA in terms of granting licences for PGD. The manner in which the Authority has exercised this discretion, however, has afforded little room for optimism in terms of ethical coherence or consistency. While the ethical principles considered in this thesis have at least been paid lip-service by the Authority and its Ethics Committee, they have been applied in a manner that suggests only a superficial understanding of their implications. In particular, although the welfare of the child figures prominently in these discussions, at no point is the Non-Identity Principle explicitly considered, nor does it appear to influence the eventual decisions at which they arrived.

The categorical imperative, or more specifically that variation thereof that requires that all individuals be treated not merely as means but also as ends in themselves, was imported into the welfare consideration in a manner that may be deemed questionable. Of more concern, however, was the apparent lack of rigour with which that principle was examined and explained, and the lack of consistency with which it

was applied to the various permutations of circumstances that might arise. It is, I have argued, by no means certain that creating a child to serve as a tissue donor violates that imperative; certainly, the interpretation of the principle adopted by Alan Donagan, one of its most influential proponents, seems almost to suggest the very opposite.

However, even if the view is taken that creating a child with the principal motive of having it serve as a tissue donor does in fact amount to a contravention of the Kantian imperative, and even if it is accepted that this in turn amounts to harming the child, it is by no means obvious how this provides a valid ground to distinguish between (a) the Hashmi scenario, (b) the Whitaker scenario, and (c) the scenario where the intended recipient is a parent. In all three cases, the child is being created to serve as a donor, and in all three cases Phase 2 screening is being carried out precisely for that end. Either the Kantian imperative is violated by none of these – as I suggest – or it is violated by all three. That being so, the decisions and rules arrived at by the HFEA certainly seem arbitrary, and it may not even be unduly cynical to suggest that they were motivated more by a desire to maintain an appearance of control - in the face of Select Committee criticism and media concern about 'designer babies' – than about legitimate concern for the 'welfare' of the resulting child.

5.1.12 Postcript

While medico-legal academics may have hoped that the Whitakers would contest the HFEA's refusal through the courts, affording us the opportunity to ascertain judicial views on the validity of the distinction upon which the Authority relied, the Whitakers availed themselves of a different option. Instead of investing money and time in a potentially fruitless challenge to the obstacles facing them in the UK, they opted instead to travel to the USA, where no such regulatory difficulties presented themselves. In June 2003, after treatment in the Chicago Reproductive Genetics Institute, Michelle Whitaker gave birth to Jamie, a healthy son whose stem cells could be used to treat his brother Charlie.[97] It is a somewhat ironic facet of the tale

[97] Dobson, R. '"Saviour sibling" is born after embryo selection in the United States', *British Medical Journal*, (2003); 326:1416 (28 June).

that the Hashmis, whose efforts to conceive a donor child were supported by the HFEA and the courts, have as yet been unable to do so.

In the event, though, had the Whitakers been prepared and able to wait another year, they would have been able to have the treatment they sought in the United Kingdom. In July 2004, following a review by its Ethics and Law Committee, the HFEA announced a *volte face* on its policy of not allowing tissue typing in such cases.[98] The rationale offered for such a decision is perplexing. In the press release announcing the change of policy, the Authority claimed that its original refusal to grant a licence in the Whitaker type case was premised upon a 'precautionary approach':

> because the technique is invasive and there was a concern about a potential risk of damaging the embryo, so tissue typing was only allowed on cells which had already been taken from the embryo for genetic diagnosis.[99]

The change of policy was, apparently, justified because

> The HFEA has now carefully reviewed the medical, psychological and emotional implications for children and their families as well as the safety of the technique. There have been three further years during which successful embryo biopsies have been carried out, both in the UK and abroad and we're not aware of any evidence of increased risk.[100]

There are a number of reasons why this explanation is unsatisfactory. In relation to the question of the 'potential risk of damaging the embryos', it is simply implausible that it took until July 2004 for the HFEA to be satisfied that no such risk need concern them. In the Introduction to the consultation paper *Sex Selection: choice and responsibility in human reproduction*,[101] considered in more detail below, the Authority noted that

> Because cells must be removed (biopsy) there is a small risk of damage to the embryo as a result of this procedure. Embryo damage during biopsy usually means that the embryos do not

[98] HFEA Press Release, 'HFEA agrees to extend policy on tissue typing', 21 July 2004, available at http://www.hfea.gov.uk/PressOffice/Archive/1090427358. Human Fertilisation and Embryology Authority Report: 'Preimplantation Tissue Typing', available at http://www.hfea.gov.uk/AboutHFEA/HFEAPolicy/Preimplantationtissuetyping/PreimplantationReport.pdf

[99] Press release, op. cit.; 'Preimplantation Tissue Typing', op. cit., at p.3.

[100] Id.

[101] Available at http://www.hfea.gov.uk/AboutHFEA/Consultations/Final%20sex%20selection%20main%20report.pdf

> develop and are not therefore transferred, so **there is no reason to believe that there is any increased health risk to a liveborn child following from this technique: embryos not damaged during biopsy should continue to develop normally.**[102]

This document was published in October 2002, a mere two months after the refusal to extend the policy on tissue typing to the Whitaker type case. Given that the research that informed the consultation document was commissioned in January 2002,[103] and that its findings were clearly available by October of that year, why would the HFEA make a decision on tissue typing based on the risk of damage to the embryo without waiting for evidence on that very risk, which it had either received by then, or receipt of which its members knew to be imminent? Such a rushed and ill-informed decision, followed by a delay of almost two years in responding to the evidence received, does not speak well of the decision-making process in the body charged with regulating PGD.

Indeed, it is notable that between the report from the HFEA's Ethics Committee,[104] which recommended that tissue typing be allowed in such circumstances, the Press Release announcing that the Authority had ignored that advice,[105] and the Minutes of the meeting at which the decision was made, not one mention was noted of this risk which apparently contributed so much to the decision.

With regard to the 'psychological and emotional implications for children and their families', these have largely been considered already in this thesis,[106] and I have suggested that denying access to PGD on this basis is difficult to reconcile with the Non-Identity Principle. Even were this view not taken, however (and it would be interesting to learn how the HFEA circumvented this argument), it is difficult to imagine how the 'further biopsies' to which the Press Release refer could have

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[102] Ibid, at Paragraph 44, emphasis added. While the risk of rendering the embryos non-viable may have concerned the Whitakers themselves, it is simply inconceivable that this was the determining factor in a consideration purporting to be concerned primarily with the 'welfare of the child', from which perspective, damaging the embryo sufficiently to render it non-viable might be supposed to be morally equivalent to deciding not to implant that embryo – the very decision for which PGD is sought.

[103] Ibid, at Paragraph 5.

[104] Available at http://www.hfea.gov.uk/PressOffice/PressReleasesbysubject/PGDandtissuetyping/Ethics%20Cttee%20PGD%20November%202001.pdf

[105] HFEA confirms that HLA tissue typing may only take place when preimplantation genetic diagnosis is required to avoid a serious genetic disorder, 1 August 2002, available at http://www.hfea.gov.uk/PressOffice/Archive/43573563

[106] See above, and also Chapter 3.

allayed any such concerns *specifically in relation to Whitaker-type cases*, since no such uses of PGD have been permitted.

In all, then, while proponents of a laissez faire approach to PGD must surely welcome this change of policy, it is difficult to discern anything in the explanation offered to restore faith in the coherence, consistency or, indeed, transparency of the decision-making process that currently regulates this technology.

5.2 Sex selection

Among the most widely publicised – and widely feared – potential applications of the Genetic Supermarket is the opportunity to select the sex of one's offspring. This possibility has formed the basis for numerous ethical evaluations, some of which are considered here, but has recently been given a more immediate concern by the attempt by Alan and Louise Masterton to secure access to this technology.[107] After their daughter, Nicole, died in an accident in 1999, the Mastertons, who also had four sons, decided to attempt to have another child. Since Louise Masterton had been sterilised after the birth of Nicole, their intention relied on the use of IVF and, in the words of Alan Masterton,

> Given our ages and the fact that Louise was going to have to undergo IVF anyway, we investigated the additional IVF procedure of pre-gender diagnosis which would have ensured another female child for our family.[108]

From the outset, the Mastertons maintained that they 'were not trying to replace Nicole', but rather 'the female element that that precious child brought to our family.'[109] Their attempts, however, were thwarted by the fact that, since 1993, the HFEA had instructed licensed providers of infertility treatment that they 'should not select the sex of embryos for social reasons',[110] a position it has recently reiterated in

[107] 'Baby sex choice couple speak out', BBC Online, Monday, 13 March, 2000, 18:03 GMT http://news.bbc.co.uk/1/hi/scotland/675652.stm

[108] 'We desperately want a girl', BBC Online, 11 December 2003.
[109] Id.
[110] Open Letter to Parliamentary Under-secretary of State, 15 July 1993. See also HFEA Code of Practice, Fifth Edition, March 2001, at Paragraph 9.9.

its response to a consultation process on sex selection.[111] In this section, I will consider the potential objections noted by the HFEA in the Consultation Document, enquiring whether they gave rise to conceptually coherent or empirically substantiated risks of harm.

The potential harmful consequences of sex selection are generally thought to relate either to the resulting child, or to third party interests in society.[112] As such, they could perhaps have been considered within either Chapter 3 or 4. However, the fact that the HFEA have seen fit to consider this issue separately from the wider issue of PGD, coupled with the fact that it has been the subject of a specific application and refusal, merits its separate consideration.

5.2.2 Sex discrimination

The danger of sex discrimination was outlined in the Consultation Document in the following terms:

> To permit sex selection for non-medical reasons is implicitly to condone sex discrimination – for example, the kind of discrimination whereby male children are favoured heirs when questions of inheritance are considered.[113]

Assuming for the moment that the designation of such choices as sexist is reasonable, does this render them harmful? While sexist choices might be thought to be inherently objectionable, can they be said to harm anyone? Mary Anne Warren certainly regarded the inherent sexism in the choice as giving rise to nonconsequentialist, rather than harm-based objections.[114] Other writers, though, have argued that sex selection, at least for sexist reasons, can be harmful either to the child born or to women in general. With regard to the latter, Helen Bequaert Holmes has claimed that such actions can result in '[s]tereotypes about the sexes becom[ing] more firmly ingrained',[115] while Michael Bayles has argued that the practice of sex

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[111] 'Sex selection for non-medical reasons should not be permitted', in *Sex selection: report summary*, Key HFEA recommendations, available at http://www.hfea.gov.uk/AboutHFEA/Consultations/Final%20sex%20selection%20summary.pdf

[112] 'I firmly disagree in calling sex selection "victimless." ... The victims of sex selection are many: selected children, their siblings, unselected children, and finally all women in society.' Helen Bequaert Holmes 'Choosing Children's Sex: Challenges to Feminist Ethics', from Joan C. Callahan, ed. *Reproduction, ethics and the law: feminist perspectives*, Indiana University Press, 1995, at p167.

[113] Consultation paper, at Paragraph 81.

[114] Warren, *Gendercide*, op. cit., at pp.83-86.

[115] Holmes 'Choosing Children's Sex', loc. cit., at p167.

selection for sexist reasons 'would probably reinforce sexist attitudes both in those who practice it and in others'.[116]

The belief that such choices reflect sexist attitudes is easily understood; why would parents go so far as to reject otherwise healthy embryos on the grounds of sex if they did not hold a marked preference for children of one sex or the other, a belief that is by definition sexist? It might be thought, however, that sex selection for family balancing – that is, its use by a family who already have a child, or children, of one sex, and who now want a child of the other sex – need not give rise to such concerns. The Mastertons, for example, have four sons whom they profess to love dearly; their desire for a daughter *as well* surely does not imply a preference for girls over boys. Hence, Savulescu and Dahl have argued:

> Since their choice is simply based on the gender of already existing children, and not on the absurd assumption that one sex is "superior" to another, the claim that these couples are making a sexist choice is an unjustified accusation.[117]

Nonetheless, it may be thought that the use of sex selection for family balancing still reflects sexist attitudes. As the HFEA Consultation Paper put it: 'it is liable to involve the imposition of stereotypical gender roles on a child of the "right" sex who has been born by this technique'.[118] A similar argument has been advanced by Wertz and Fletcher:

> Even in the U.S. where most couples desire to have one child of each sex, there are preferences for boys. Even if the selection were in favor of girls, however, the fact remains that sex selection is inherently sexist because it is premised upon a belief in sexual inequality.[119]

Proponents of such a view might, for example, enquire precisely what the Mastertons mean when they speak of restoring 'the female element' to their family. Does not this statement reflect an inherently sexist view that a girl child, whatever her

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[116] Michael Bayles, *Reproductive Ethics*, New Jersey, Prentice-Hall, Inc., 1984, at p36. See also Buchanan, Brock, Daniels and Wikler, *From Chance to Choice*, op. cit., at p184: 'The practice depends on and reinforces a systematic bias against women. That bias is indefensible on grounds of justice and works in various ways to produce injustice against women.'

[117] Julian Savulescu, and Edgar Dahl, 'Sex selection and preimplantation diagnosis: A response to the Ethics Committee of the American Society of Reproductive Medicine' *Human Reproduction* (2000); 15(9): 1879-1880, at p1880.

[118] Consultation paper, at Paragraph 97.

[119] Dorothy C. Wertz and John C. Fletcher. 'Fatal Knowledge? Prenatal Diagnosis and Sex Selection' *Hastings Center Report*, May/June 1989, 21-27, at p22.

individual characteristics, will bear similarities to Nicole that set her apart from her brothers?[120]

The objectionable aspect of such values might be thought to be twofold. First, there is the danger that such preconceptions will impact deleteriously on the new child, perhaps by constraining her life choices according to her parents' preconceived notions about how a girl should behave.[121] It might also be thought that the child may sustain psychological or emotional harm when it learns that it was selected for sex.[122]

Such a suggestion may be thought far from implausible. For decades, it has been known that, from infancy, how children – 'normal', non-sex selected children - are treated depends substantially on their gender, or on which gender they are perceived to be. One of the most famous demonstrations of the latter was in oft-cited the Jack-in-the-Box experiment.[123] This gauged the responses of a selection of adult observers to the perceived emotional responses of young children to a startling stimulus (a jack-in-the box). The study famously revealed that the same response was typically deemed to be 'fear' when the child in question was believed to be female, and 'anger' when it was believed to be male.[124]

Such preconceived attitudes, whether conscious or subconscious, are often thought to characterise parents' relations with their children. Furthermore, in those cases where prospective parents have gone to such lengths as to seek out, and perhaps pay for, sex selection, it is perhaps predictable that such attitudes already exist. If this is so, then *whatever* child that is born to such parents will be subject to these attitudes, and whatever harms may be thought to accompany them; the harms, then, will eventuate irrespective of whether they are permitted or prohibited from using PGD to determine the sex of their child.

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[120] A similar point is made by Bayles, *Reproductive Ethics*, op. cit., at p35. See also Buchanan, Brock, Daniels and Wikler, *From Chance to* Choice, op. cit., at p184.
[121] John A. Robertson, 'Preconception Gender Selection', *The American Journal of Bioethics Online* Winter 2001, 1(1): 2-9, at p4.
[122] Consultation paper, Paragraph 89.
[123] Condry, J. and Condry, S. 'Sex differences: A study of the eye of the beholder'. *Child Development*, (1976); 47: 812-819.
[124] The children were dressed either in pink or blue, but this did not, contrary to the expectations of the observers, correspond to their actual gender.

In addition, these potential harms might be thought to be analogous with those arising from heightened parental expectations more generally. In Chapter 3, I argued that any harm arising from such unfair expectations or constraints would be unlikely to be harms on balance, that is, harms so severe that a proportionate step would be to prevent the child's birth altogether. To deny access to these technologies to parents like the Mastertons would be implicitly to proclaim that, for such children, the benefits of existence would not outweigh the disadvantages of a sexist environment. I suggested earlier that this was an unpersuasive conclusion, and submit that that would seem also to be the case here.

If sex selection is not bad for particular children, then, what of the notion that they are potentially harmful to women in general, that – as Holmes, Bayles, and others have argued - they do not only passively reflect but actively reinforce sexist attitudes within society? The precise mechanism by which such reinforcement might take place is not examined by any of its proponents cited above, but it might be thought that a societal context in which sexist choices were common, well publicised and permitted would encourage sexist attitudes in others.

Such a concern might be thought to bear similarities to the expressivist concerns considered in Chapter 4, the difference being that in this case the preconceived prejudicial attitudes are against women (or less commonly, men) rather than those characterised as 'disabled'. They are also subject to some similar responses. In much the same way as some writers have argued that it is possible to wish to avoid the birth of a disabled baby without harbouring negative opinions about disabled people per se, so too has it been argued that sex selection of one's offspring need not be a manifestation of negative attitudes towards one or other sex. Just as deaf parents may wish to have a child that will share in their experience of a deaf life, Mary Anne Warren has observed that women may have a rational reason for preferring daughters:

> A son might be able to share most of their particular interests and activities, but he could not share the basic experience of being female in a society which still values males more highly.

> However much he may sympathize with the plight of women, he will still be a member of the more privileged sex.[125]

Such a choice then will not be inherently sexist, but will rather be a rational response to an already heavily gendered society. In other societies, Warren notes, the pre-existing sexism could lead women in the other direction; in a society that favours boys and men, a woman who wishes the best for her child may well try to ensure that child is male (whatever difficulty we would find in reconciling such an attempt with the Non-Identity Principle), and it would, Warren maintains, be unfair to blame women for contributing to the sexism that characterises that society when they are in reality merely trying to make the best they can of life within its confines:

> So long as these many forms of oppression persist, it is absurd to suggest that women are guilty of sexism if they wish to have male children in order that the latter may enjoy the freedoms which women are still denied.[126]

The apportionment of blame, however, does not necessarily answer the consequentialist question of whether such a choice is potentially harmful. We may understand and sympathise with the motivations of women who make such decisions within a context that was not of their making, while still recognising that '[e]ach act of son-preference ... further devalues women as a class.'[127] However, it is as well to keep in mind that, in such contexts, prohibition of sex selection may be inflicting non-trivial harms on the women who seek to avail themselves of this technology.

Ruth Macklin's interviews with Indian women led her to conclude that, whatever the ethical problems with sex selection as practiced there, 'to prohibit it by law is probably causing more harm than good to the very people it seeks to protect – members of the female sex.'[128] In the absence of any prospect of instantly reversing centuries of entrenched sexism, Macklin maintains, the choice is between, on the one hand, allowing the use of sex selection, and on the other, further limiting the already narrow range of choices open to such women, and in so doing forcing them to accept the inevitable social stigma (and sometimes ostracisation and even violence)

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[125] Warren, *Gendercide*, op. cit., at p87.
[126] Id.
[127] Holmes 'Choosing Children's Sex', loc. cit., at p167.
[128] Ruth Macklin, *Against Relativism: Cultural Diversity and the Search for Ethical Universals in Medicine*, Oxford, Oxford University Press, 1999, at p154

attendant on the failure to produce a son. In such circumstances, she concluded, the greater of the two evils lies in martyring actual, existing women on the altar of western egalitarian values.[129]

Furthermore, the potential harm to 'women as a class' seems to rely on the assumption that sex selection will be used predominantly to choose boy rather than girl children; without this assumption, it is impossible to see how the technique could be regarded as devaluing women. If such a belief transpired to be well founded, then it may be that other, more concrete harms could result from the inevitable distortion of demographic trends. It is with this possibility that the next section will be concerned.

2.2.3 Demographic distortions

Is it likely that preimplantation sex selection would result in a skewing of the balance between males and females? And if it did, would this be harmful? The former assumption certainly seems to underpin many feminist critiques of sex selection.[130] As I will demonstrate below, however, the available evidence, inconclusive though it is, suggests that such a fear may be exaggerated. First, though, to the question of whether, and why, a society with more males than females would be harmful to anyone.

Perhaps the most controversial claim has been that a society with significantly more males than females is likely to be more aggressive and violent. This belief may derive either from a perception that males are inherently more violent than females, or a perception that the relative absence of women would lead to tensions among (particularly) young men who would become rivals for the attentions of the relatively scarce available women. Whether societies with majority male populations are indeed more violent is a complex sociological question, and any answer to it must take account of myriad variables over and above gender ratios. Furthermore, as

[129] See also Warren, *Gendercide*, at pp.196-197.

[130] 'Few doubt that if sex selection were cheap and effective, many more males than females would be born.' Helen Bequaert Holmes 'Choosing Children's Sex: Challenges to Feminist Ethics', from Joan C. Callahan, ed. *Reproduction, ethics and the law: feminist perspectives*, Indiana University Press, 1995, at p152. More emotive is Robyn Rowland's claim that sex selection technology 'could mean the death of the female.' 'Motherhood, patriarchal power, alienation and the issue of "choice" in sex preselection', from G. Corea, et al, *Man-Made Women* (Bloomington: Indiana University Press, 1987), at p75.

Warren has pointed out, we must be wary of overly rash assumptions about the causal relationship between the trends:

> Where there is an association between the two phenomena, it is at least as likely that the violence of the society contributes to son-preference and the consequent high sex ratios than the reverse. The American and Australian frontiers were probably not violent because of the scarcity of women. Rather, women were scarce because life on the frontier was difficult and unsafe.[131]

The second concern about societies that are male-dominated in population terms relates to the position of women within them; the fear is that they will become male-dominated, or more male-dominated than they already are, in the other, patriarchal rather than demographic, sense. One version of this claim bears a marked resemblance to the claim from Tom Shakespeare that the political strength of disabled people would decline in proportion to their numbers; thus, Rowland has argued that

> Women are the most exploited, manipulated, oppressed and brutalized group in the world, yet we have the numbers. What would our status be as a vastly outnumbered group? And how many women would be prepared to accept a world where their value as breeders or sexual objects only would be recognized?[132]

In response to the suggestion that the status of those women who are born into such a society might rise as a result – 'Because of her scarcity woman will be "highly-valued"' - Rowland maintains that 'she will be valued for sexual and breeding purposes rather than for her intrinsic worth as a person.'[133] She then proceeds to catalogue a range of specific problems that a reduction in the percentage of women would pose, including the empirically unsubstantiated assertion that 'I would suggest that that female suicide rates would escalate.'[134]

Warren has examined the various claims relating to the likely status of women within male-dominated societies, and has found the evidence and arguments to be unpersuasive in either direction. Insofar as any specific prediction can be discerned

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[131] Warren, *Gendercide*, op. cit., at p127.
[132] Rowland, 'Motherhood, patriarchal power, alienation and the issue of "choice" in sex preselection', loc. cit., at p83.
[133] Ibid, at pp.81-82.
[134] Ibid, at p83.

as to the likely effect, Warren claims that the effect for 'women' is likely to depend on the pre-existing nature of the gender relations in that society. Thus, she suggests:

> Where polygyny is not practiced and single women have few means of earning an adequate living, a shortage of men is bound to result in more women living in poverty. In contrast, women who have adequate means of survival outside of marriage may benefit from low sex ratios.[135]

Furthermore, the effect on 'women' will depend on precisely which women we are discussing:

> The potential benefits to women of increased sex ratios include greater opportunities to form stable relationships with men, and a greater subjective sense of power within the traditional female roles. The potential liabilities include a loss of freedom to deviate from these traditional roles, exclusion from most high-status positions, and the absence of a strong feminist movement to combat such injustices.[136]

Whether a particular woman stands to benefit in such a society, then, will depend in part on whether she, personally, has interests bound up with a stable traditional role as a wife and mother, or with opportunities to pursue other, less traditional avenues, such as a career.

Such predictions, as Warren concedes, are necessarily highly speculative. There is simply insufficient empirical data to allow for a confident prediction of how a greater gender imbalance would affect the position of women. Fortunately, for present purposes, such data may not be required in order to respond to this particular suggested harm. For the available data relating to attitudes to sex selection suggest that the possibility of a predominantly male society is highly remote.

The literature review that formed part of the HFEA's report following the consultation process found that 'There were surprisingly few general population surveys regarding attitudes to sex selection published since 1990',[137] and that 'The majority of specific sex selection surveys appear to have been carried out in the US

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[135] Warren, *Gendercide*, op. cit., at p135.
[136] Ibid, at pp.135-136.
[137] Dr. Catherine Waldby, 'Literature Review and Annotated Bibliography: Social and Ethical Aspects of Sex Selection', at p2. Interestingly, the opinion poll conducted by MORI on behalf of the HFEA, and the results of which form part of the report, did not attempt to fill this lacuna by enquiring whether respondents would wish to utilise these technique, had they the option. Instead, the poll asked only about attitudes to regulation of other people's choices. See Michele Corrado and Konrad Collao, 'Sex Selection – Public Consultation: Research Study conducted for Human Fertilisation and Embryology Authority'. January 2003.

during the 1970s and 1980s.'[138] These were the studies that formed the basis of Mary Anne Warren's research, and which led her to conclude that there was, at that time, no empirical basis for the fear that, first, there would, in the USA, be substantial demand for sex selection, and secondly, that among those who did make use of it there would be a pronounced preference for boys rather than girls. What the research to which Warren referred *did* suggest, however, was a slight statistical preference for first children to be boys. This led her to speculate as to the effects of a society of 'big brothers and little sisters'.[139]

The most recent research pertaining to UK attitudes referred to in the HFEA report was reported in a letter to *The Lancet* in 1993, and recorded the attitudes of already pregnant women.[140] The results revealed that, of the 1824 women recruited into the survey, '58% of responders said they had no preference for a child of a particular sex; 6% said they would prefer a boy and 6% a girl; 12% would quite like a boy and 19% a girl.' The authors conceded that '[t]hese data tell us nothing of what women would do if they could select the sex of their baby', but nonetheless noted that 'most pregnant women have no particular preference', while 'of those who expressed a sex preference for their unborn child, that preference was as likely to be for a girl as for a boy.'[141] This led them to conclude that 'fears of unbalancing the sex ratio are not supported by our data'.[142]

The HFEA review also referred to research published in 1995 which examined the ethnic composition and specific gender preferences of over 800 couples seeking sex selection at the London Gender Clinic.[143] Although this is informative from another point of view (see below) the self-selecting nature of the couples in question sheds no light on the likely rates of uptake of such services were they widely available.

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[138] Ibid, at p3.
[139] Warren, *Gendercide*, op. cit., at pp.138-142.
[140] Statham, Helen; Green, Josephine; Snowdon, Claire; France-Dawson, Merry. 'Choice of baby's sex', *The Lancet* (1993); 341(8844): 564-565.
[141] Ibid, at p565.
[142] Id.
[143] Liu, P. and Rose, G.A. 'Social aspects of > 800 couples coming forward for gender selection of their children' *Human Reproduction* (1995); 10(4): 968-71

Since the publication of the HFEA report, a further study[144] has suggested that a significant minority – 21% - of the UK population would be willing to pay £1250 to avail themselves of sex selection were the option available, with 7% claiming to be undecided as to whether or not they would use it.[145] (This was contrasted with only 6% of Germans responding that they would exercise the choice.[146]) Does the prospect of as many as 30% of the population potentially availing themselves of sex selection techniques lend substance to the fears of demographic skewing?

The authors of this particular article certainly did not interpret their data as a cause for alarm. Rather, they noted that while 3% of respondents would prefer only boys in their family, this was largely counteracted by the 2% who wanted only girls, while 68% favoured an equal number of boys and girls, and 16% 'simply do not care about the sex of their children'.[147] While a slightly higher number of respondents indicated that they would prefer a boy (16%) rather than a girl to be their first-born child, a large majority (73%) expressed no preference, and 10% preferred a first-born girl. If such data accurately reflect the views of the UK population as a whole, then it seems unlikely that the suggested advantages enjoyed by firstborn children[148] need significantly reinforce the existing advantages enjoyed by males.

While it would be foolhardy to infer too much from a single study, it is perhaps equally rash to assume that the preference for boys would be both present and substantial enough to cause demographic problems. To date, none of the published studies have provided evidence of a significant parental preference for boys over girls; insofar as any common preference is discernible, it is for an equal number of children of each sex, or at least one of either sex within a bigger family. Whether or not such preferences derive from sexist assumptions about the likely characters and attributes of, respectively, boys and girls, they certainly do not provide a reason to

[144] Dahl, Hinsch, Beutel and Brosig. 'Preconception sex selection for non-medical reasons: a representative survey from the UK', *Human Reproduction* (2003); 18(10): 2238-2239.
[145] The fact that 71% of respondents had no interest in choosing their babies' sex did not prevent the BBC from the reporting the study under the headline 'Britons "would choose baby's sex"'. BBC Online, 25 September 2003.
[146] Dahl, Beutel, Brosig and Hinsch, 'Preconception sex selection for non-medical reasons:a representative survey from Germany', *Human Reproduction*, (2003); 18(10): 2231-2234.
[147] Dahl, et al, 'a representative survey from the UK', loc. cit., at p2238.
[148] See Warren, *Gendercide*, op. cit., at pp.138-142.

believe that a laissez faire approach to preimplantation sex selection will give rise to significant demographic distortions.

Of course, if such trends did begin to manifest themselves, and if they led to harmful consequences, a case could be made for adopting measures to constrain choice. But for the time being, when what little evidence is available suggests that most prospective parents would either have no interest in making this choice, or would actively strive to promote gender balance, worries about skewing gender ratios seems prematurely pessimistic.

Furthermore, the widely held beliefs that sex selection in other societies (India and China are oft-cited examples[149]) would be used overwhelmingly to avoid the birth of girls, Macklin and Warren have both provided reasons to doubt whether prohibitions in those communities would actually benefit women there. In any event, the fact that a particular technology would present problems in another part of the world hardly constitutes a reason to prohibit its use in the United Kingdom, any more than the practice of foot-binding in China would have been ended by banning the sale of bandages from London pharmacists. [150]

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[149] See, for example, Buchanan, Allen; Brock, Dan W.; Daniels, Norman; Wikler, Daniel. *From Chance to Choice: Genetics and Justice*. New York, Cambridge University Press, 2000, at p.183

[150] Over the past decade, the HFEA's position on sex selection appears to have been influenced to some extent by the belief that, while there may be little demand for sex selection among the general population, it is likely to be used in a more problematic way by 'certain ethnic communities'; see Open letter to Parliamentary Under-secretary of State, 15 July 1993. Such concerns may have been lent some credence by the research of Liu and Rose, which revealed that, of the 800 or so couples in the survey, all of whom were attending a London clinic offering sex selection, 57.8% were of 'Indian' ethnic origin, while 'Asian and Middle Eastern couples overwhelmingly wanted boys, whereas European couples showed a slight preference for girls.' The notion that sex selection is likely to give rise to demographic problems among UK ethnic minorities was, however, called seriously into question by the Qualitative Research Study commissioned by the HFEA, which found 'the views expressed amongst Asian groups very similar to other groups. That is, from a personal, moral perspective, they felt serious medical conditions [the] only justifiable reason for sex selection.' In marked contrast to the apparent expectations of some commentators, most respondents from the Asian groups (there were separate groups for Hindu/Sikh and Muslim respondents) felt that 'it was discriminatory to argue that girls were less desired or valued than boys', and that 'girls were as likely, if not more likely, to become economically successful and want to look after elderly parents.' *Sex Selection – Policy and Regulatory Review. A Report on the Key Findings from a Qualitative Research Study*. October 2002. Of course, responses in a 'focus group' might be thought a less reliable guide than what people actually do in practice. But since preimplantation sex selection has been unavailable in the UK since 1993, such surveys of professed opinion are the most reliable indicator we have, and certainly more accurate than unsubstantiated generalizations about ethnic minorities.

Chapter 6 Conclusion

I have argued, then, for a laissez faire approach to PGD, whereby potential parents might avail themselves of any tests they choose, whether these are for what are commonly regarded as disease traits, for HLA compatibility, for embryonic sex, or for any other reason, including selecting for what are conventionally regarded as disabilities. In allowing them this unconstrained choice, we respect and further their interest in reproductive liberty, and acknowledge that the outcome of that choice will impact more significantly upon their lives than on the lives of anyone else.

The obvious exception to this claim might be the resulting child, but as I argue in Chapter 3, it will very rarely be the case that the children of the Genetic Supermarket could be said to be harmed on balance; the mere fact that their very existence is contingent upon their parents' choice will almost invariably mean that they have received a net balance of benefits over harms, even where their unorthodox origins expose them to possible harms (such as unusual parental pressure) that other children will be spared.

The Non-Identity Principle has been widely recognised among the literature I have reviewed, but few authors have been willing to follow it to its logical conclusion. Rather, prominent bioethicists such as John Harris and Julian Savulescu have sought to argue that prospective parents are ethically obliged to avoid the birth of handicapped children (although Harris certainly would stop short of imposing a legal obligation to this effect, he does not share my view that such decisions are ethically neutral). They have done this by departing from the Person-Affecting axiom and importing Non-Person-Affecting considerations such as a concern for the amount of suffering in the world.

In Chapter 3, however, I sought to demonstrate that recognising even an ethical obligation to this effect was inevitably problematic, as it seems to impose an obligation to refrain from having any children at all. The alternative NPA principle seemed more sophisticated in that it balanced the concern for suffering with attention to the amount of 'happiness' introduced to the world. However, an ethical obligation to increase the happiness in the world, or the balance of happiness over suffering,

seems to give rise to the equally unpalatable conclusion of a universal imperative to reproduce, at least up to the point where each additional child will no longer yield a marginal utility gain.

The alternative to these utilitarian NPA approaches is a recognition that our ethical obligations should be concerned exclusively with those interests that people (and, presumably, sentient non-humans) actually have. This concern logically extends to those future people who will exist, but not to those who, as a consequence of our decisions, will never be more than potential future people. The fact that they have never had, and never will have, subjective interests places them outside our sphere of ethical concern.

The contention that choice in reproductive matters is among our most powerful interests is a difficult one to prove empirically, but it is a view widely (if not unanimously) shared in the literature I have reviewed. Where my approach departs from that advocated by John Robertson or Joel Feinberg is in that I do not seek to impose artificial or arbitrary constraints on that interest. I would not, as Feinberg does, seek to designate certain interests as 'inherently immoral', and therefore outwith our sphere of ethical concern. Nor do I agree with Robertson that only a reproductive choice that 'plausibly falls within societal understandings of parental needs and choice in reproducing and raising children'[1] should be protected.

Such approaches, I have argued, are open to a charge of arbitrariness (who decides which interests are excluded, or which parental choices are sufficiently in keeping with societal expectations?) and may indeed surrender the Harm Principle of which Feinberg, and perhaps also Robertson, may be seen as champions, to the legal moralism, or 'tyranny of the majority', against which it is supposed to serve as a bulwark. Hence, even choices that may be seen as unorthodox, trivial or motivated by vanity or selfish motives are bound up with the interest in reproductive choice, and require a substantial ethical counterweight if they are to be constrained.

[1] John A. Robertson 'Extending preimplantation genetic diagnosis: medical and non-medical uses.' Comment in: J Med Ethics. 2003 Aug;29(4):213-6, at p.216

Elsewhere in Chapter 2, I have attempted to defend the Non-Identity Principle from some recent philosophical challenges conducted within the Person-Affecting axiom, respectively, James Woodward's 'No Trade-offs' view, and Robert M. Green's 'Generic Child' approach. The latter, I have argued, can be challenged even while accepting its central premise, that interests/rights are not interchangeable fungibles. While this may be so, what we can say is that all rights can be waived, and there may be occasions where it is appropriate to assume that a party will elect, retrospectively, to waive his right in recognition that an infringement of a particular right brought him a net balance of benefits over harms.

This is the sort of assumption on which we operate when we push someone out of the way of a swerving bus, or perform a life-saving procedure on him while he is unconscious. In both cases, the interference with bodily autonomy is justified, we think, because of the overwhelming likelihood that the individual would, if we could but ask him, agree to this intrusion. The situation is analogous, I have argued, when the party in question is as yet no more than a potential person. Even were we to accept Woodward's contention that such an entity enjoys a right to, or possesses an interest in, a certain quality of health, we are acting reasonably when we assume that he would waive this right in return for the chance of existence. Provided his life is of a minimally decent quality, he would almost certainly accept its limitations as a price worth paying.

I also sought to show that Woodward's position involves a particular, and by no means uncontentious, idea of what ethical demands a potential future person might reasonably make against his parents. An absolute standard of health, or economic or emotional security, would potentially debar the majority of the planet's population from reproducing. A better standard, we might think, would be a relative obligation, whereby a potential parent is required to do her best (or a percentage of her best) for the future child, but should not be blamed for providing it with less – whether in material or natural assets – than other parents are capable of providing, or indeed than she might have been able to provide for another child.

Green's 'Generic Child' approach was, I argued, fatally undermined by the author's own concession that it was little more than a philosophical thought experiment,

employed to give voice to a non-rational aversion to the more counterintuitive conclusions of the Non-Identity Principle. To speak of *a* potential future child is to ignore the obvious fact that the decision is between several rival potential future people; which ever one the parents choose, none of the others can be said to have benefited or harmed in the slightest degree, not least because their potential interests will never crystallise into actuality.

In Chapter 4, I considered some of the possible third party harms, or negative externalities, that it is sometimes argued will result from the Genetic Supermarket. In so doing, I concentrated on what I regard as the most plausible and least far-fetched of the fears. I did not, for example, consider the possibility – frequently seen in newspaper letter columns, but rarely in peer-reviewed bioethical literature – that unrestrained access to PGD would result in a physiologically homogenous society of blond-haired, blue-eyed children. Such a dystopian scenario seems too obviously predicated on a lack of understanding of genetics – couples without the requisite genes for blue eyes or blond hair will be unable to pass those traits on to their offspring, however many embryos they conceive – and human psychology; many people, it seems safe to assume, want to have their own genetic children because they want their children in some ways to resemble them.

The concern that the Genetic Supermarket will harm disabled people, however, is far from fanciful, but in this chapter, I sought to demonstrate that some of the harms referred to by critics of PGD may in fact be best addressed by a less, rather than more, restrictive approach. In particular, the expressivist objections so passionately voiced by writers like Marsha Saxton seem more likely to be addressed by a state policy of neutrality with regard to PGD; the status quo, which allows its use only for the elimination of embryos likely to become disabled children (what Saxton deemed 'people like us'), is almost certain to convey an offensive message to disabled people who already feel devalued.

The alternative approach which I have proposed here would allow those parents – presumably the majority? – who wish to use PGD for screening out genetic disorders, but it would further allow it for those like the Mastertons, who wish to select their child's sex, like the Whitakers, who seek to ensure a tissue match, and

any successors to Sharon Duchesneau and Candy McCullough, who wish to maximise the chances that their child shares their particular 'disability'. In so doing, society would send a message of support for parental choice, whatever form it may take, rather than for only *certain* selected parental choices. While this will not serve as a panacea for the painful feelings of rejection – or worries that they *would*, had the choice been available, have been rejected - spoken of by some disability activists, it will at least weaken the sense that 'society' is attempting to 'eliminate the disabled'.[2]

Such an approach, though, gives rise to further difficulties regarding the extent to which society should provide, rather than merely allow, access to PGD, and I readily concede that my conclusion with regard to this question is decidedly more tentative. I have suggested that the prospect of wealthy parents being able to further advantage their children with 'golden genes' (at least insofar as these were present in their own gametes) can perhaps be accommodated within a Rawlsian concept of distributive justice, according to which how we respond to disparities in unearned assets is more important than the fact that such disparities exist. Whether or not we allow the Genetic Supermarket to come about, wealthy parents will find ways to ensure that their children have 'unfair' advantages in life. And with or without the Genetic Supermarket, natural assets such as strength, dexterity and beauty will be 'unfairly' distributed. If we are concerned with justice, we must devise a means to ensure that those blessed with such environmental or natural assets do not profit unfairly as a result. Curtailing access to PGD would be to address one, relatively minor symptom, rather than to address the underlying disease itself.

Yet a 'hard' version of the Genetic Supermarket seems at its most harsh and unfair when it abandons those less wealthy parents who know themselves to be carriers of some relatively serious genetic disability to the whims of the chromosomal lottery. Even were the sensible, and presumably non-offensive, concession to be made whereby PGD was provided for the avoidance of aneuploidy,[3] or slightly more controversially, for the avoidance of Worse Than Nothing (WTN) lives, this would

[2] A perception, it might be thought, that is likely to be strengthened by the Government's unambiguous and overwhelming enthusiasm for genetic screening for, inter alia, Down's syndrome, as recently expressed in the White Paper *Our Inheritance, Our Future: Realising the Potential of Genetics in the NHS*, Cm. 5791, June 2003; see, in particular, Para. 3.28.

[3] It being difficult to see how anyone could be offended by the screening out of an embryo that is unlikely to survive even until birth.

still mean that less wealthy couples had no means available of avoiding a child affected with, for example, cystic fibrosis or muscular dystrophy, neither conditions that would plausibly render a life worse-than-non-existence, but both of which could impact significantly on the lives of these families.

A somewhat glib response would be to say that a Rawlsian policy of redistribution would reduce the divisions between rich and poor, such that no-one would be unable to afford PGD. However, such a noble aspiration is unlikely to offer much comfort to those who find themselves locked outside the Genetic Supermarket's doors. Perhaps an analogous approach could be taken to that employed towards cosmetic surgery, according to which 'elective' procedures are at the individual's own expense, but 'remedial' work is provided at state expense. Yet this necessarily involves an exercise in line-drawing which would fall foul of the very expressivist objections I hoped the laissez faire approach would avoid.

I concede that I have been unable to devise a solution to this problem that does not seem likely either to offend disabled people, or to abandon less wealthy couples to the reluctant parenthood of seriously (but not WTN) disabled children. Nonetheless, it may be that a less restrictive approach, whereby PGD was still *provided* for relatively serious conditions, but was in addition *permitted* for all traits, might still be somewhat less offensive to disabled people than the status quo, where the choices of deaf or achondraplasiac couples to have similarly affected children would be prohibited outright.

Furthermore, it might be hoped that the questions of justice with which the Genetic Supermarket presents us may lead us to challenge or revise some of our prior assumptions about fairness and desert. The 'lottery ticket' approach to distributive justice, according to which the winners are free to enjoy the fruits of their good fortune provided that everyone had a roughly equal chance of winning, is, I suggest, impossible to reconcile with the notion that we do not deserve that which was attributable neither to our choices or our efforts. The belief that rejecting the Genetic Supermarket involves rejecting the accumulation of genetic advantage in the hands of the wealthy overlooks the fact that genetic advantage, *whoever* possesses it, is by its very nature undeserved. Those concerned with just distribution of resources

should, as Rawls maintained, be as concerned with undeserved, inherited genetic advantage as with undeserved, inherited wealth.[4]

In my final chapter, I considered the actual decisions that have, to date, been made by the HFEA and, on one occasion, by the courts. It is my contention that the approach of the HFEA to tissue typing has suggested an organisation seeking to synthesise various ethical principles (welfare, the Kantian imperative, virtue ethics) while doing justice to none. The result was a distinction that was highly questionable both on ethical grounds – one child apparently condemned to die while another was denied an existence, and the parents were deprived of their existing child – and in terms of consistency. Although the HFEA has recently revised this policy, it has couched this about face in terms that offer little grounds for optimism in relation to future decisions.

In relation to sex selection, the current policy seems to derive from a hybrid of deference to public opinion, concern for demographic effects and a deep distaste for what is perceived as the inherent sexism in such choices. In relation to the first of these, the question of whether public opposition to a practice should justify its prohibition takes us back to the very origins of the Harm Principle, which, both in its Millian formation and as utilised by Hart in the 1950s, maintained that mere disapproval, however widely held, was an insufficient basis for criminalisation.[5] Anyone with the merest sympathy for the Harm Principle and the liberal sentiments underlying it will be unlikely to be impressed with an approach that makes individual liberty contingent on majority approval.

The demographic worries, I have shown, are challengeable on empirical grounds – there is simply not enough evidence to allow any sort of accurate prediction of how sex selection will be used, though such evidence as is available diminished rather than enhances such concerns. For those who fear that a society dominated by one or other gender is both a realistic possibility and a worrying one, the consolation exists that this is not a 'stable door' issue where a failure to legislate immediately might see

[4] A fact largely lost upon the unapologetic meritocrats of the current UK Government; see Alex Callinicos, *Equality*, Cambridge, Polity Press, 2000, at pp. 38-39.
[5] See Chapter 2 of this thesis.

the damage ensue almost overnight – as might be thought to be the case with genetically modified organisms or xenotransplanation. Rather, the use of preimplantation sex selection could be monitored, with a view to imposing restrictions if and when a credible body of evidence showed that it was being used in harmful ways.

Perhaps most importantly, I have sought to demonstrate throughout this thesis that the language of harm and interests continues to occupy a central place in bioethical discourse, and among those whose positions cast them as the Genetic Supermarket's doormen, but that these concepts are often applied inconsistently and without sufficient philosophical rigour. The failure of the HFEA in any of its various reports and press releases concerning tissue typing to acknowledge the Non-Identity Principle is an astonishing oversight, given the profound consequences this notion would have upon the Authority's decisions.

And it may be that the conceptual confusion penetrates to a higher level still. As I argued in Chapter 3, the position adopted by the UK courts with regard to Worse Than Nothing lives in the context of selective non-treatment of neonates seems difficult to reconcile with the outright rejection by the Court of Appeal of wrongful life suits, but the latter is utterly impossible to reconcile with the apparent requirement in Section 13(5) of the 1990 Act that reproductive service providers consider the welfare of any future child before assisting a woman to become pregnant. Either it is possible to compare the quality of a life with non-existence, or it is not; a state of affairs wherein judges to seek to avoid such a comparison on the grounds of its purported impossibility, while at the same time Parliament expressly requires medical professionals to undertake it, is simply untenable.

The approach I suggest would bring consistency to this area, interpreting s.13(5) so as to prevent the creation of WTN lives, while allowing wrongful life actions to be raised on behalf of those born into such lives. Furthermore, I submit, my approach also brings both areas of law into line with the Non-Identity Principle, by regarding any other sort of life (we might, I suppose, speak of Better Than Nothing lives, or even, in more cumbersome terms, of Lives Neither Better Nor Worse Than Nothing)

as insulated by the Non-Identity Principle against both the prospective prohibition of s.13(5) or the retrospective remedy of wrongful life.

I began this thesis with a 30-year-old vision of the future. Nozick's notion of a Genetic Supermarket, unconstrained by state interference, at first glance sounds like one of the more outlandish approaches to PGD, on the outer borders of ultra-libertarianism. It is my contention, though, that if carried to its logical conclusion, it might actually address some of the objections to PGD, while recognising and respecting the vastly important interest each of us possesses in planning our own reproductive future.

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